

**EMPOWERING PEOPLE WITH DISABILITIES
TO LIVE, WORK, LEARN, AND THRIVE**

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C O N T E N T S

	Page
Opening Statement of Senator Robert P. Casey, Jr., Chairman	1
Opening Statement of Senator Mike Braun, Ranking Member	3
PANEL OF WITNESSES	
Brent Orrell, Senior Fellow, American Enterprise Institute, Washington, DC .	5
Erin Willman, Founder and CEO, White Cane Coffee Company, Warren, Pennsylvania	6
Lydia Brown, Director of Policy, National Disability Institute, Washington, DC	8
Mayor Neil McDevitt, Mayor of North Wales, North Wales, Pennsylvania	10
Ai-jen Poo, President, National Domestic Workers Alliance, Executive Direc- tor, Caring Across Generations, Chicago, Illinois	12
APPENDIX	
PREPARED WITNESS STATEMENTS	
Brent Orrell, Senior Fellow, American Enterprise Institute, Washington, DC .	32
Erin Willman, Founder and CEO, White Cane Coffee Company, Warren, Pennsylvania	34
Lydia Brown, Director of Policy, National Disability Institute, Washington, DC	36
Mayor Neil McDevitt, Mayor of North Wales, North Wales, Pennsylvania	39
Ai-jen Poo, President, National Domestic Workers Alliance, Executive Direc- tor, Caring Across Generations, Chicago, Illinois	41
STATEMENTS FOR THE RECORD	
The American Network of Community Options and Resources Testimony	49
Dr. Amy Houtrow Testimony	51
Anna Corbin Testimony	52
Community Legal Services of Pennsylvania Testimony	53
Dr. Dennis B. Downey Testimony	54
Cindy Duch Testimony	55
Gary Blumenthal Testimony	56
Eugenia Bond Testimony	57
Jacquelyn M. White Testimony	58
Jonathan Cunningham Testimony	59
Julie Ann Lieberman Testimony	60
Julia Barol Testimony	61
Kate Dempsey Jones Testimony	62
Kathy Brill Testimony	63
Liberty Resources, Inc. Testimony	64
Linda Carmona-Bell Testimony	65
Lisa Lightner Testimony	66
Mark Friedman Testimony	67
Matt Aaron Testimony	68
Maureen Cronin Testimony	69
Meghann Luczkowski Testimony	70
Nancy Murray Testimony	71
Nancy Thaler Testimony	72
James W. Conroy and Karen Ann Hayes Testimony	73

C O N T E N T S

STATEMENTS FOR THE RECORD (CONT'D)

	Page
Pennsylvania Statewide Independent Living Council (PA SIL) Testimony	74
Pennsylvania Advocates and Resources for Autism and Intellectual Disabilities (PAR) Testimony	75
Pennsylvania Autism Society of America Testimony	76
Pennsylvania Department of Human Services Testimony	77
The Partnership for Inclusive Disaster Strategies Testimony	78
Stacey Jarett Levitan Testimony	79
Institute on Disabilities at Temple University Testimony	80
Sherri Landis Testimony	81
Katy Neas Testimony	82
Dr. Tina Paone Testimony	83
Tom Carasiti Testimony	84
Vision for Equity Testimony	85

EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE

Thursday, December 12, 2024

U.S. SENATE
SPECIAL COMMITTEE ON AGING
Washington, DC.

The Committee met, pursuant to notice, at 10 a.m., Room 106, Dirksen Senate Office Building, Hon. Robert P. Casey, Jr., Chairman of the Committee, presiding.

Present: Senator Casey, Gillibrand, Blumenthal, Warren, Kelly, Warnock, Braun, and Rick Scott.

OPENING STATEMENT OF SENATOR ROBERT P. CASEY, JR., CHAIRMAN

The CHAIRMAN. Good morning, everyone. The Senate Special Committee on Aging will come to order. We want to welcome you to the final hearing of the Aging Committee's final hearing of this Congress, the 118th Congress. The name of this hearing is; Empowering People with Disabilities to Live, Work, Learn, and Thrive.

This is my last hearing as the Chair of the Committee, and I've been honored to serve as chair and as a longtime member. I've served as a member of the Committee for these 18 years, four of those as ranking member and four as chair, and I'm proud of the work that this Committee has done. We've accomplished much under my tenure, and I'm sure years before that.

I'm thankful for the support of my colleagues on both sides of the dais, and it's been a pleasure to work with Ranking Member Braun, and we wish him the best of luck as he starts his new work as the Governor of Indiana in January.

For more than 60 years, this Committee has championed issues facing older adults, including protecting against frauds and scams, ensuring nursing homes provide safe, quality care, and advocating for older workers. Many of these efforts have been bipartisan.

In the last eight years, the Committee has expanded its reach to champion the rights of people with disabilities. People with disabilities deserve the opportunities that all Americans have and access the same access that's available to each and every American. This means the opportunity for a person with a disability to secure a quality education, to receive comprehensive healthcare, to earn a living wage, and to save for the future. We've seen great progress in these efforts with the leadership of strong advocates, many of whom are here today and their families. Today's hearing will focus on that work and opportunities that still lie ahead of us.

Let's start with home and community-based services known by that acronym, HCBS. Americans with disabilities and older adults continue to need access to reliable long-term care services and supports. There are more than 700,000 people on waiting lists for Medicaid home care services, and they have to wait for over four years on average to begin those services, to have the benefit of those services.

The workers who provide long-term care services in all settings earn approximately \$15 an hour, and nearly 50 percent of these workers rely on programs such as the Supplemental Nutrition Assistance Program for support. We should not have seniors and people with disabilities waiting for years, years to access supports to live in their own homes and be active members of their own communities, and we should value the workers who provide care and support for people with disabilities and older adults. Direct care workers should be earning a livable wage and not relying upon public assistance to survive.

I'm grateful for the work of the Biden Administration to make home and community-based services a priority, as did I, and a number of members of both the House and the Senate. There's still much work to be done in the years ahead. Today's hearing will focus on people with disabilities in the work, in the workplace. While the number of people with disabilities who work has increased in the past 10 years, their participation in the labor force is still over just half of that of the general population.

During the pandemic, thousands of people with disabilities continue to work in grocery stores, warehouses, and hospitals, providing essential services for all Americans while they put their own health, and often their lives, at risk. We need to ensure that people with disabilities have the resources, accessibility, and accommodations they need to be successful workers. Likewise, we need to ensure that government services at all levels of government are accessible to people with disabilities.

Several years ago, I learned about Ron Biglin, a veteran from Clarks Summit, Pennsylvania, my home county, Lackawanna County. Ron was unable to access his health benefits at the VA, the Department of Veterans Affairs at their website because that website was not accessible to Ron Biglin and many others. Through my oversight efforts, we learned that in 2019, only eight percent of the information on the VA's website was accessible. No longer. Those numbers have gone way up.

In the intervening years, the remainder of the Federal Government websites and other technology were no more accessible than the VA. In that year, 2019, we took a close look at it, so we're making progress, but we have a long way to go. Much more work to be done on improving access.

Whether it's improving access, or eliminating discrimination, or providing accommodations to make it possible for people with disabilities to be full participants in our society, this is the work that must continue. It also, when we work on these issues, it also makes our society a better place for all of us people with disabilities or not.

During my time in the Senate, people with disabilities and their families have shown me and demonstrated to me in more ways

than one the power of advocacy, determined advocacy. They've championed the rights of people with disabilities to serve in the workforce and to save for their futures. They've fought for people with disabilities to be able to live in their homes and to be active members of their communities, and they've successfully defended against cuts to Medicaid and Social Security and other programs. Our witnesses today have been central to that advocacy work. I look forward to hearing from them about some of the achievements of the disability community and the goals ahead.

Now, just as, as part of this hearing, but even, even beyond the scope of today's hearing, I'm issuing five issue briefs. I'll just hold them up in summary fashion. I won't read through all of them, but these issue briefs will deal with a number of topics. Two of the topics we'll cover here today; access to home and community-based services, and government accessibility. The other briefs will address or do address lowering prescription drug costs, ensuring economic security for older adults and improving nursing home care.

This Committee, the Aging Committee, has a legacy of providing resources to our Senate colleagues and to others throughout the Nation about issues facing people with disabilities and of course, older adults. Many of these resources are available both in English and in Spanish. I hope that these issue briefs will be similarly valuable to the future work of the Senate. We all need to continue the work to support people with disabilities and older adults so they can thrive in their communities, and I look forward to hearing from our witnesses about the work that lies ahead.

I'll turn to Ranking Member Braun for his opening remarks.

**OPENING STATEMENT OF SENATOR
MIKE BRAUN, RANKING MEMBER**

Senator BRAUN. Thank you, Chairman Casey, and for all the witnesses being here today. People with disabilities have the same hopes, dreams, and expectations of respect and dignity as all of us. One shared reality is the importance of a strong economy.

In recent years, people with disabilities have achieved record gains in jobs, in labor force participation. A good economy accomplishes more for people with disabilities, and I think any federal program ever could, but federal spending has been excessive and it has jeopardized these gains. Trillions in unnecessary spending still has inflation too high up over three percent again from last year. We've had 10 years of inflation crammed into the last three years.

Correspondingly, high interest rates have pushed mortgage rates over seven percent and cooled the job market. The employment rate fell again last month, the second straight decline, the most vulnerable that are hit the hardest by this economic term turmoil, and that means seniors and people with disabilities. They feel the pinch at the grocery store when they look for a new home and when they need a job.

I am confident that the new administration will turn the economy around. The last thing older Americans and Americans with disabilities need is a tax hike, but the debt problem causing our economic challenges has been bipartisan. We've generated that from both sides of the aisle. National debt at the end of Fiscal Year

2024 was 99 percent of GDP, the highest since World War II. By 2030, forecasted to be nearly 140 percent of GDP.

We now spend more on interest payments than we do on the entirety of national defense. Last month, the national debt rose to over 36 trillion, and in 10 years, its forecast to be 56 trillion. Thirty-six trillion is over \$100,000 for every person in the United States. Think about what that means for benefits and services. Its seniors and vulnerable generations need right now.

If we do not grapple with the national debt, the numbers never relent. They just don't go away, and that means it'll be even harder and harder to deal with it down the road. We'll have slower growth, you'll end up probably having more inflation and even higher interest rates. It's very easy. It just takes a little self-discipline. All other parts of our economy have to live within that framework, local and State governments. Seniors will struggle, people with disabilities will suffer, and every generation will be worse off.

I look forward to hearing about economic trends affecting seniors and Americans with disabilities, and I hope we keep our reckless spending problem front of mind in this discussion here today.

Mr. Chairman, I yield back.

The CHAIRMAN. Thank you, Ranking Member Braun. Now we'll turn to our witness introductions, and I'll turn first to Ranking Member Braun for the first witness introduction.

Senator BRAUN. Brent Orrell is a senior fellow at the American Enterprise Institute. Mr. Orrell specializes in job training and workforce development with a special focus on disadvantaged populations. He is also an expert on the impact of technological change in the workforce, which is rampant here in this day and age. Mr. Orrell previously held multiple roles in government, including at the Department of Labor, and Health and Human Services. Thank you for testifying here today. Thank you.

The CHAIRMAN. Thank you, Ranking Member Braun. I'll now turn to the remainder of our witnesses. Our first witness is Erin Willman. Erin is the founder and CEO of the White Cane Coffee Company in Warren, Pennsylvania. And I've been there. It's a great coffee company in Northwestern Pennsylvania.

Erin started White Cane Coffee Company in 2019 to provide self-sustaining jobs for people with disabilities living in rural communities, including for herself and her brothers, so, Erin, we're grateful you're here. Grateful you made the trip. Coming from Warren County's quite a ride, so we're grateful you're took time to be with us.

Our third witness is Lydia Brown. Lydia Brown is the director of policy at the National Disability Institute and an adjunct professor of disability studies at American University and Georgetown University. Counselor Brown's Research focuses on economic security and wealth building for individuals with disabilities. Counselor Brown, we're grateful you're here today, and thanks for sharing your expertise with us.

Our fourth witness is Mayor Neil McDevitt. Mayor McDevitt is the Mayor of North Wales, Pennsylvania in Montgomery County in the southeastern corner of our State, so, we have representation from the northwest and the southeast all in one hearing. Mayor

McDevitt was elected as mayor, I guess, elected in 1921 and started serving in 1922, and is believed to be the first deaf mayor elected to a municipality in the United States of America, so, Mayor, thank you for being with us today and sharing your expertise and insight.

Our fifth witness is someone I've known a long time, a great advocate. Ai-Jen Poo is the president of the National Domestic Workers Alliance. She is also co-founder and director of Caring Across Generations, a coalition of organizations working to strengthen the caregiving infrastructure for America's families. Ai-Jen is a recognized expert in family and elder care, and has been recognized by Time Magazine as one of the 100 most influential people in the world. Ai-Jen, we're grateful you're here today, and really have enjoyed working with you. And thank you for sharing your expertise with us.

We'll start with our first witness Mr. Orrell for his testimony, and then we'll go right down the line from there.

**STATEMENT OF BRENT ORRELL, SENIOR FELLOW,
AMERICAN ENTERPRISE INSTITUTE, WASHINGTON, DC**

Mr. ORRELL. Chairman Casey, Ranking Member Braun, other members of the Committee, thank you so much for the opportunity to discuss the critical issues facing aging and disabled workers in America. I will focus on two dimensions; the practical demands of the economy and the moral responsibilities of our society.

The largest factors shaping America's economic future is demographics. Our population's aging rapidly, with fertility rate falling, and the median age rising from 29.5 years to 38.9 years since 1960, from 2000 to 2005, our workforce grew by 12 million workers. Between 2017 and 2022, that figure was just 1.7 million.

Demographics drive growth, older populations work and consume less, reducing economic dynamism. While we cannot quickly reverse population trends, we can engage marginalized groups, older workers, people with disability, people with criminal records, and others. To help sustain growth in a time of worker shortages, no individual's contributions can be overlooked or minimized.

Second dimension, that of the moral responsibility, is that being American means believing in the dignity of every person. Work provides a vital way to express that dignity, aligning skills and interests with the needs of the economy and our fellow citizens. For older and disabled Americans, this is no less important. If we neglect to uphold and support their participation in the workforce, we will not only hurt our economy, but fail to uphold the core value that every human being is entitled to equality and dignity.

The participation of older workers in the workforce has been rising steadily, with 19.2 percent of Americans age 65 or older now working or seeking work. In 2000, 25 percent of post-retirement age seniors were employed compared to 32 percent today. By 2032, older workers will make up 8.6 percent of the labor force compared to 6.6 in 2022. Similarly, the employment rate for individuals with disabilities reached 22.5 percent in 2023, and that's the highest since data collection began in 2008.

However, this is still just one-third of the rate for workers without disabilities, and the employment rate for those with disabilities

is twice as high as the general population. Many disabled workers face additional barriers such as limited access to full-time jobs with benefits, and roughly half of disabled Americans are also over the age of 65, which compounds their difficulties in the labor market.

Advances in artificial intelligence, automation, assistive technologies, all offer opportunities to remove barriers and expand employment for individuals with disabilities. Screen readers, voice recognition software, and AI-powered communication tools enable individuals to perform tasks once inaccessible for older workers.

AI tools can simplify complex tasks, and telework platforms can allow them to remain at home and work from there. However, the benefits of technology will only be realized if we have an intentional design and policy support behind it. Policy makers should be looking at ways to make these technologies accessible and affordable.

In terms of recommendations, we need to be promoting inclusive employment practices in the workplace. We need to invest in education and training to expand access to learning across the lifespan to help older adults and people with disabilities gain new skills, and we need to leverage technology for inclusion. I think this is an area that is ripe for public and private investment to adapt these new technologies to the needs of the elderly or older workers and people with disabilities.

The challenges posed by our demographic shifts and gaps between work and older and disabled job seekers are formidable, but they are not insurmountable. By fostering workforce inclusion for older and disabled Americans, we can strengthen both our economy and our social commitment to dignity and equality. And together, we can build a labor market that reflects both our values and maximizes the potential of every person.

Thank you so much for the opportunity to offer testimony.

The CHAIRMAN. Mr. Orrell, thank you for your testimony. I'll turn next to Erin Willman. Erin?

**STATEMENT OF ERIN WILLMAN, FOUNDER AND CEO, WHITE
CANE COFFEE COMPANY, WARREN, PENNSYLVANIA**

Ms. ERIN. Hello, I'm Erin Willman. I am the founder and CEO of White Cane Coffee, and I would like to thank Senator Casey, and Senator Braun, along with the rest of the members of the Aging Committee for inviting me to speak on subjects that both I and many in the disabled community face.

A lot has happened since I was here in February. I have received an incredible number of calls and emails from disabled persons and organizations that assist the blind and disabled. The common theme of those messages is that things are actually changing. We are not yet where we need to be when it comes to disability access and acceptance, but we are getting there. It brings me great joy when I hear of disabled people in my community getting good, paying jobs, and not being relegated to sheltered workshops for less than minimum wage.

A few weeks ago, an engineer from a large manufacturer in our county visited our coffee factory to see how we adapted our workspaces and machinery to accommodate our employees. He honestly

wants his company to be inclusive. I consider this a huge step forward.

On a side note, I had the honor to run for PA's and State representative for District 65. Even though I lost my election, I found the majority of people that I met were accepting of me as a viable candidate. The best part of the experience was having younger people come up to me and tell me that because of my running for office, they too feel that they can also create change in their community in both large and small ways.

Today, I would like to talk about accessible education and how it can be bettered with the RISE Act. People ask me all the time if I went to college. The answer, I am sorry to say, is no. Despite the fact that I graduated high school at the age of 15, I felt wholly unprepared for the challenges my disability would bring me in a college setting.

However, my hope is that others in the disabled community won't feel that trepidation when they seek out higher education, but I recognize that there are things that need to be changed for that to happen. At this time, people with disabilities who wish to go into college and need accommodations to be successful have to prove that they are disabled through costly testing, even if they were born with a disability or have previous documentation from when they were in high school.

I remember how nerve wracking it was for those in my life who were heading off to college. I can't imagine putting more stress on a person with a disability because they have to prove their disability to get the support they need to thrive. If a person already has documentation that they're disabled, that should be sufficient. I don't believe that there are any prospective students who somehow became able-bodied would want to ask for the same assistance they had before when they were disabled.

While proving that a person has a disability is disheartening enough, there's also the issue that many schools make it difficult to find out what sort of assistance and accommodations are available to disabled students. When looking into a college a student wants to attend, they have to comb through websites and visit the campus, and even in some cases, contact the administration personally just to find out if the school has the accommodations that they would need to access the education offered by the college.

If one school does not have the accommodations a particular student needs, the student will have to repeat this search process as many times as needed until they can find a school that is suitable. Not only can that process be stressful, it can be so disheartening as to possibly turn them away from the idea of going to college at all.

It doesn't have to be this way though. If schools were upfront and transparent on what accommodations are available, the stress of finding the right school would be lessened significantly, making the transition to higher your education easier.

Now I believe it is time to give the spotlight to our educators. We all have had at one point in our lives a teacher on who has inspired and helped us become—and helped us find our path in life, so, I believe that they should have help to continue that work on a wider scale.

It's an unfortunate truth that many teachers do not have the training that they need to accommodate a student with a disability. However, under the RISE Act, this is a problem with an easy solution. The RISE Act would allocate funds to college administration so that the faculty has the tools and know-how to be able to teach all of their students so that they are able to thrive in their classroom. By educating our educators, our colleges can be a place where everyone can succeed no matter what.

I have always been extremely passionate about education. I believe that it can open doors and build bridges. It can lead to good jobs and a better life. Education expands a person's opportunities in life. It's why I work with so many schools for the disabled so that those students can create a brighter, more inclusive future.

America is known as the land of opportunity. By implementing the RISE Act, many disabled people across the Nation will have the opportunity to seek out higher education without the worry, they will not belong. Something as simple as that would change their lives. If you change one life, you change the world. It is time to change the world. Thank you.

The CHAIRMAN. Ms. Willman, thank you for your testimony. Counselor Brown, you may begin.

**STATEMENT OF LYDIA BROWN, DIRECTOR OF POLICY,
NATIONAL DISABILITY INSTITUTE, WASHINGTON, DC**

Ms. BROWN. Good morning. My name is Lydia Brown, I am director of public policy at National Disability Institute, as well as a proudly disabled advocate. Thank you for the opportunity to provide testimony before the Committee today.

Disabled people represent at least 20 percent of the U.S. population or more than 65 million people, although the real number is likely higher than current surveys indicate including people who have newly acquired disabilities due to long-Covid. Our community faces deep economic disparities with poverty and unemployment rates for people with disabilities, about twice those of non-disabled people, along with higher rates of homelessness and food insecurity.

According to NDIS research, disabled people are more than twice as likely to be financially vulnerable as non-disabled people, only 51 percent of working age disabled adults are confident they can pay their bills on time, and 46 percent of disabled adults carry more debt than they can manage.

Fewer women with disabilities, disabled people of color, and LGBTQ people with disabilities are financially healthy than people with disabilities who are men, White, or non-LGBTQ. Over 30 percent of disabled households have an income below \$15,000, a rate 5.6 times higher than for households without a disability, and those numbers are substantially higher for Latinx and Black households with disabilities.

These economic disparities in earnings savings, banking, and wealth building are exacerbated for the many people with disabilities who rely on means-tested public benefits to survive. Many disabled people rely on Medicaid as the sole provider of long-term supports and services; help with eating, taking meds, getting dressed, even positioning their bodies. These services that can keep people

in their own homes instead of nursing homes and institutions, as well as enable people to enter and remain in the mainstream workforce.

Eligibility for Medicaid, however, is tied to eligibility for supplemental security income, SSI. A beneficiary is prohibited from having more than \$2,000 in countable assets if single, and \$3,000 between both spouses if married, asset limits that were last updated in 1989.

A person with a disability who wants to work and is able to work for any amount of hours is precluded from seeking the same array of opportunities as a non-disabled person if that disabled person relies on Medicaid funded support to live at home or get to work.

Some disabled people turn down promotions, hours increases, and raises, in order to maintain eligibility for Medicaid, because accepting the increased wages would not cover the gap if they lost their benefits. These asset limits can force people to choose between going without necessary medication, or paying their light bills, or buying enough food, or making rent. An emergency bill of \$2,100, a modest amount for some hospital stays, could leave a disabled person on SSI with no savings at all and snowballing consequences of carrying the debt.

Ten years ago, Senator Casey's leadership in introducing and passing the ABLE Act changed the game. People whose disabilities began before age 26 can now access a savings vehicle that can conserve up to \$100,000 total without their savings counting against them and determining eligibility for SSI and for Medicaid.

Money in an ABLE account can be used for a wide range of qualified disability expenses, including otherwise unaffordable assistive technology and healthcare, as well as educational and employment-related costs. For many disabled people on Medicaid, an ABLE account is also their only available means to save for retirement.

In recent years, NDI also championed Senator Casey's leadership in passing multiple improvements to ABLE, including the ABLE Age-Adjustment Act, which widened ABLE eligibility to people whose disabilities began by the age of 46. A provision that comes into effect a year from now and will ensure eligibility for more than 6.2 million additional people with disabilities, including one million veterans.

As we look forward to the future of the ABLE Program, we know there are many opportunities for further growth and improvement, especially to benefit the most impoverished people with disabilities who may not be able to make contributions to an ABLE account, and disabled people who are working and earning enough to make contributions in excess of the current \$18,000 annual limit.

Members of the Senate are currently considering a range of improvements for the ABLE Program, all of which would greatly increase financial capability for people with disabilities. The ABLE Direct Deposit Act and the ABLE Employment Flexibility Act would codify common-sense improvements like allowing direct deposits and employer retirement contributions into enable account.

The ABLE Awareness Act, the ABLE Tomorrow Act, and the EN-ABLE Act, would collectively support engagement and education efforts around ABLE to increase enrollment for eligible beneficiaries,

protect against Medicaid claw backs after a beneficiary's death, and allow one-time lump sum contributions over the annual limit.

Language in these bills would also permanently adopt provisions, allowing additional contributions to ABLE accounts for working people with disabilities, a savers credit for ABLE contributions and rollovers from 529 Education savings accounts to ABLE accounts.

Opportunities remain for increasing economic opportunity and participation for people with disabilities who deserve to have the full range of financial choices and freedom as people without disabilities. Future legislative efforts can expand eligibility to more people with disabilities, protect rights of youth in the foster system and adults under guardianship, and increase disabled people's ability to save for retirement on par with non-disabled people.

NDI believes in a future where all people, both disabled and non-disabled, can be assured of basic economic security and opportunity. This includes a future in which disabled workers can save for retirement on par with non-disabled workers, and disabled people have no ceiling on the amount of income they can earn and savings they can build just like everyone else.

Senator Casey, please know that you have made a difference. Thank you, again, today, for the opportunity to speak before this Committee. I urge you to continue championing policies that advance equity, financial inclusion, and economic opportunity for people with disabilities. Together we can create a society where all people have the resources and opportunities to achieve financial stability and economic security.

The CHAIRMAN. Counselor Brown, thank you very much, and thanks to the work of NDI. Mayor McDevitt.

**STATEMENT OF MAYOR NEIL MCDEVITT, MAYOR OF
NORTH WALES, NORTH WALES, PENNSYLVANIA**

Mr. MCDEVITT. Good afternoon. As a resident of the Commonwealth of Pennsylvania, I'm heartened to sit before Senators Casey and Fetterman on this special day, Ranking Member Braun, and other members of the Committee. Thank you for welcoming me today.

I sit before you today as the mayor of North Wales Borough, an amazing community of 3,400 residents in Montgomery County just outside of Philadelphia. That may not be remarkable in itself. There are, after all, over 519,000 elected officials in the United States today. I am unique in that I am, as far as we're able to tell, the first deaf person to be elected to the Office of Mayor who uses American Sign Language as their primary means of communication. I'm also a proud alum of Gallaudet University right here in Washington, DC.

As an elected official who uses American Sign Language, and the first one in the Commonwealth of Pennsylvania, I found out very quickly where the barriers are. In a tiny community like North Wales, I'm blessed that the borough council and borough manager wisely had funds set aside in their budgets long before I was elected to ensure accommodations for people with disabilities.

I know that this is fairly unique to small communities across the United States. The sad truth is that I don't have enough funds available to cover all of my interpreting needs, and I need to pick

and choose where I spend those funds. Senator Casey, I shared the challenges I had with you and your staff in your research. You also found another barrier that exists for people with disabilities who want to get involved in politics.

That is, if a person with a disability simply runs for any office, be it paid, barely paid, or unpaid, they can lose their Supplemental Security Income, SSI, or Social Security Disability Insurance Income SSDI, even if they don't raise any money or they lose their election.

In two separate congressional sessions, Senator Casey presented two bills. The Removing Access Barriers to Running for Elected Office for People with Disabilities Act would address the discriminatory language in the Social Security Act that penalized people with disabilities for running for office.

The second was the Aid Accessibility and Inclusion to Diversity Local Government Leadership Act of 2024 to address my challenge, that is, for small communities like North Wales Borough. It would establish a grant to reimburse those municipalities for accommodation expenses they incur for any elected and appointed officials with disabilities.

These bills are a critical step toward addressing a glaring gap in the demographics of our elected officials. Out of the over 519,000 elected officials across the country, I am personally aware of only five who use American Sign Language, nationally, today. If our elected officials truly represented our populations, we'd have over 1,550 elected officials today using American Sign Language. Extending that further, current estimates say that 10 percent of all elected officials have a disability of some type, but 28.7 percent of the population has a disability.

The unfortunate conclusion is that our elected officials are not representative of the people whom they serve. The reality is that the Americans with Disabilities Act, ADA, is the last great civil rights bill that was passed with true bipartisan support. As I said during my remarks at the White House's Disability Pride event a few months ago, "I woke up one morning with rights I did not go to bed with." The ADA made millions of Americans first class citizens in our own communities overnight.

In the 34 years since the ADA was passed, our political will toward safeguarding these vital human and civil rights have weakened significantly. I call on congressional leadership and Senators from both parties to recommit to protecting these vital rights and services for millions of Americans. I ask you to look beyond the rhetoric of soundbite politics, and listen carefully to the people who would actually be affected by the policies that have been suggested or proposed by members of the incoming administration.

The next Congress can take positive and proactive steps toward ensuring the civil and human rights of people with disabilities. First, the passage of Senator Casey's bills referenced earlier would be an excellent first step toward ensuring that our elected officials are truly representative of the communities whom they serve.

Congress must also ensure that all United States citizens are able to freely participate in every American experience. This requires full funding and dedication of the U.S. Department of Justice's Civil Rights Division, to work closely with municipalities and

counties to ensure that all Americans have full access to vote and to take part in their communities.

Senator Casey, you have been a steadfast ally of North Wales Borough, the Commonwealth of Pennsylvania, and millions of disabled and deaf Americans. We owe you a debt that can never be repaid. Thank you.

The CHAIRMAN. Thank you, Mayor. Thanks very much. I really appreciate you being here with us. Ai-Jen Poo. Thank you, Ai-Jen.

**STATEMENT OF AI-JEN POO, PRESIDENT, NATIONAL
DOMESTIC WORKERS ALLIANCE, EXECUTIVE DIRECTOR,
CARING ACROSS GENERATIONS, CHICAGO, ILLINOIS**

Ms. POO. Chairman Casey, Ranking Member Braun, and members of the Committee, thank you for the opportunity to testify this morning. My name is Ai-Jen Poo, and I'm the president of the National Domestic Workers Alliance, and executive director of Caring Across Generations. We are proud members of Care Can't Wait; a national coalition working to create good care jobs and guarantee affordable care for all who need it. I represent the family caregivers and the care workers who are struggling within an anemic patchwork system to provide essential support to disabled people and older adults.

In the United States, Federal Medicaid dollars, not Medicare, Medicaid pay for the vast majority of long-term care, including wages for direct care workers, but Medicaid long-term care programs suffer from persistent gross underinvestment. As a result, over 710,000 people remain on waiting lists for Medicaid, home, and community-based services, or HCVS.

Unpaid family caregivers and underpaid care workers are left to fill the gaps. Unpaid caregiving is worth more than \$1 trillion per year. Direct care workers, who are majority women of color and immigrants, earn an average of just \$25,000 per year. Nearly half rely on public assistance to make ends meet, and the workers, therefore, that we are counting on to care for us, cannot care for themselves or their own families on the wages they earn. Many are forced to leave these jobs for fast food or retail jobs where they can earn more, increasing training and turnover costs for employers impacting the quality of care for families and feeding a workforce crisis that exists in states across the Nation.

Thankfully, there are solutions. The American Rescue Plan Act resulted in over \$36 billion in investments toward Medicaid, home- and community-based services, and higher wages for direct care workers. All 50 states took this funding because of the urgent need for care in every State, but this funding is short-term set to expire in March 2025, leaving the system vulnerable at precisely the time when we need more access to services, not less.

Every day in America, 10,000 of us turn 65, and we're living longer than ever before. The number of adults over the age of 85 is expected to double by the year 2040. We will need a thriving direct care workforce to help meet the demand care jobs already consistently rank among the largest and fastest growing occupations in the entire economy because of the overwhelming need.

Here, again, we have solutions we can invest in raising wages and supporting workers' rights to join a union and negotiate collec-

tively for better wages and benefits. We know this works, and there's enormous return on this investment, not only in the dignity for the workers and the people who rely on their services, but the economic opportunity they enable, both for disabled people and working family caregivers who need care in order to work. Or in Senator Casey's words, "Some of us need a bridge or a tunnel to get to work and others need care."

This is all out of reach without increasing federal funding for Medicaid. It is shocking that the discussion has returned once again to cutting Medicaid at the exact moment when we should be investing in it. Reductions in Medicaid funding will heighten the workforce crisis, the care crisis, push higher costs onto states that can't afford it. States will be forced to cut services and limit eligibility, which will literally put millions of lives at risk.

Instead of cuts, we should be passing policies like the HCBS Access Act, the Better Care Better Jobs Act, the Long-Term Care Workforce Support Act, the HCBS Relief Act to support freedom, dignity, and security of disabled people, and really of all of us. These bills all share one sponsor, Senator Bob Casey.

In closing, I want to thank you, Senator Casey. You are a generational leader on these generational challenges that we face as a Nation. Millions of lives have been improved because of your leadership and hard work, this arena of policy and the advocates who work on them who have filled this hearing room this morning are exponentially stronger because of you.

While it is daunting to face the challenges ahead without you at the helm, we are determined to carry the torch forward truly. Truly, thank you, Senator.

The CHAIRMAN. Ai-Jen, thank you so much for those words, and for your leadership, and your ever-determined and effective advocacy, and we'll get to our questions now. Senator Gillibrand, I've been instructed to yield to you, if you want to start.

Senator GILLIBRAND. Mr. Chairman, I hope no one instructed you to do anything, but I really think this hearing is such a testament to who you are and what service you've provided for this community your whole public career, and I have personally admired having you as my chairman, and watching you and seeing how you've led this Committee on such important issues. It is a true honor and privilege to get to serve with you, and I think I speak for the entire community that benefits from this Committee and your work that we are eternally grateful.

I am very excited that we have this panel of witnesses today. Each of you contribute so much to the conversation that we're having and so much to the solutions that this Committee is trying to put forward. I've been very proud to work on and lead the Domestic Workers Bill of Rights Act with my colleague, Senator Casey. It ensures that workers caring for our families are respected, are protected, and our compensated fairly for the vital work that they do every day for our families and our communities.

Ms. Poo, what should we know about how the Domestic Workers Bill of Rights strengthens the paid care workforce and help support family caregivers? What change and improvement for people with disabilities could we expect to see if it was actually enacted?

Ms. POO. Thank you so much for your leadership and for this question, Senator Gillibrand. It's nice to see you. The Domestic Workers Bill of Rights Act will ensure the care workforce is treated like other workers in our economy with access to a safe workplace, sick leave, overtime pay, and protection from discrimination and harassment.

A standards board will allow employers, enforcement agencies, and workers, to work together to improve conditions, which will help secure the workforce that then supports disabled people and family caregivers, people who need the supports and the services. Family caregivers also support this bill because they recognize that a protected care workforce is really the backbone of the economy, and that care work is the work that makes all other work possible. We must ensure that these jobs are quality jobs and many domestic workers are also disabled, so this is about opportunity and security for all of us.

Senator GILLIBRAND. Thank you so much. Working age adults with disabilities remain employed at less than half the rate of people without disabilities, and are twice as likely to live in poverty. We have to do much more to support employers and workplaces that have made employment truly accessible and inclusive for people with disabilities. Ms. Willman, what are the biggest obstacles you faced founding the White Cane Coffee Company, and what about operating it now?

Ms. WILLMAN. I think some of the hardest things that we faced when we first opened up White Cane Coffee is sort of getting the word out. Having people take us seriously as a company. Many people saw us as the cute little coffee shop run by a blind girl. I am a serious business woman, and I want to make that clear. I don't want to be just the best blind business owner. I just want to be the best.

We strive for that every day. I have won international awards, and I am very proud of that, and even more so, I am proud of my work staff for helping me achieve these goals.

Senator GILLIBRAND. How could we help entrepreneurs who want to start businesses like yours, Ms. Willman?

Ms. WILLMAN. I think what we need to do is, again, treat them like people and support them in every way we can, and with having the RISE Act implemented, it will have people be more educated to be able to start their own businesses, and also, if we—you know I've lost the word. If we implement apprenticeships more often, more students will be able to have firsthand work so that whenever they go to start their own job, they can feel a sense of confidence. Thank you.

Senator GILLIBRAND. Mr. Orrell, this is something we obviously want to work on a bipartisan basis, and I know that there could be also some tax policies that could help businesses like the White Cane Coffee Company to be able to empower their employees with disabilities to live full independent lives.

I also have met many people with disabilities who had sponsors to help them do their jobs in the workplace, and to be an advocate within the workplace for them to make sure that they can work at their fullest capabilities, so, Mr. Orrell, what do you think on those topics?

Mr. ORELL. Thank you for the question. I think that we need to focus on the incentive side of the equation which is how can we support businesses in making this transition? Whether it's redesigning jobs, redesigning workplaces, or some other kinds of investments in bringing more disabled people into the workforce. I think that's far more effective than trying to impose a mandate on employers.

I think that actually is counterproductive. It builds resistance. What we need to do is to show business people that with a combination of the talent that disabled people have, and the support that they can get through tax incentives and other incentives that it's a good business decision for them.

The CHAIRMAN. Thank you, Senator Gillibrand, we'll turn next to Senator Scott.

Senator Rick SCOTT. Thank you, Chairman. First, I want to thank everybody for being here. First, Chairman Casey and Ranking Member Braun, thank you for your service. Chairman Casey, it's been great to work with you over the past six years as you highlight the needs of older Americans. I want to thank you for your hard work over the last couple years in these Committee meetings. I know it's a lot of work, and you've done a great job.

Ranking Member Braun, I'm proud to have the opportunity to call you a friend and a partner on so many things to help make—work for the American people. We came up at the same time. You're going to be a great Governor. You're going to do a great job. I'll do everything I can to help you become the number one Governor in the country.

We're top co-sponsors of each other's legislation. Over the past six years, the time we've both been up here, I've joined 71 pieces of legislation from your office, and you've joined 67 for mine. For both of you, I look forward to watching what you do with your post-Senate careers. I know what Senator Braun's going to do, and Senator Casey, I wish you the best of luck.

Everyone in the United States, regardless of disability, deserves to have a chance at the American Dream. Overregulation, outdated laws inhibiting this need to be reviewed, cut, and rewritten. For example, as of today, individuals who are in the supplemental security income program can only have \$2,000 in assets, with couples only allowed \$3,000, jointly. This law hasn't been updated in decades and is hurting everyday Americans. It's time for a change.

I'm proud to join my colleagues in supporting the SSI Savings Penalty Elimination Act to encourage financial stability for individuals in the SSI program. Individuals with disabilities shouldn't be held back from receiving their federal benefits due to the government not being compliant with federal accessibility laws.

In 2022, The Washington Post issued an alarming report that blind and disabled veterans can't properly access via websites. That's wrong. Last year, Chairman Casey and I, introduced the Veterans Accessibility Act to address this issue. I'm happy to continue this fight in the next Congress to make some meaningful reforms and help our veterans with disabilities.

Mr. Orrell, how can we ensure that reforms to SSI encourage work and independence rather than perpetuating dependency?

Mr. ORELL. Well, I think the good news is that we are seeing in the economy, given how robust it has been, significant improvements in workforce participation. Some of those people probably in the past might have wound up on disability payments, so, and this is something that Senator Braun addressed in his opening statement, which is the most important factor in keeping people from becoming dependent is a robust economy that pulls people into the workforce.

I do think that there's a need to address the incentives within these disability programs so that the first thing that we're thinking about is employment, and then we think about whether that person can benefit from access to Social Security Disability Income, SSI, and other programs, veterans benefits and so on, so that we have all of the arrows kind of pointed in the right direction.

Work should be the default and access to benefit programs should be the exception. I don't want to see anybody who needs benefits denied, but I do think that we have had a history in the last several years, or decades really, of using these disability programs to warehouse people, and I think that's wrong. It's bad for the economy, it's bad for the people, and it's something that we really need to revisit across the board in disability programs.

Senator Rick SCOTT. What would be your number one market-based solution to help people that have disabilities?

Mr. Rick ORELL. I think that we have to recognize that mandating higher wages, mandating inclusion policies that require certain numbers of people with disabilities have the effect of making access to jobs more difficult for people with disabilities, so, I think we need to—in some ways, it's things that we should try to avoid doing if we can avoid the disincentives toward work.

Senator Rick SCOTT. Ms. Willman, I look forward to coming to your coffee shop someday. How would raising the SSI asset limit impact the ability of individuals with disabilities to start and grow with their businesses?

Ms. WILLMAN. I believe that they would be less afraid to make the steps that they need to make, and it takes a lot to start the business and to have enough assets. Assets will likely exceed the SSI cap, so, if that has changed, more people with disabilities would be able to start their own businesses.

Senator Rick SCOTT. Thank you. Thank you, Chairman. Thank you, Ranking Member.

The CHAIRMAN. Thank you, Senator Scott. As many of those who attend our hearings know, Senators are in and out. Some coming to ask questions, some, some here for a period of time and have to leave for other Committee hearings, other commitments on a Thursday, so, we'll have some Senators who will be here for questions and some who won't. I know earlier we had both Senator Blumenthal and Senator Kelly here, and we're expecting more Senators in just a little while. I'll start my questions, and then I'll turn to Ranking Member Braun, and we'll see where we are with other Senators coming in and out.

I wanted to direct this question to both Ai-Jen Poo, and Counselor Brown. As the panel noted, people with disabilities represent at least 20 percent of the U.S. population, or more than 65 million people. I think most experts believe that number might be an

under count, but that's roughly the number that that most people point to.

It's been 34 years since we passed the so-called ADA, the Americans with Disabilities Act. Yet every day, people with disabilities continue to face barriers. We hear about this all the time. Barriers in making a living wage, barriers to building wealth, barriers to accessing higher education, as Erin Willman outlined, and of course, barriers to securing home-and community-based services.

It's those barriers that continue to be the subject of a lot of our work, and will continue to be part of the challenges ahead of us, and ahead of the next Senate, the next administration, and I'm sure many after that.

Despite the many advances that have been made to secure equal opportunity for people with disabilities, there's still so much more that we have to do, and I wanted to ask both Counselor Brown and Ai-Jen Poo with an eye toward the next Congress and the next administration, what disability policy do you think is the most important to address? And I know you might have a list, and that's okay, but if you could just itemize and maybe prioritize.

Ms. BROWN. This is Lydia speaking. Most importantly, for many people with disabilities, we need to continue to have access to and increase support for home and community-based services. These are services that are available and funded through Medicaid.

I am echoing some of what Ai-Jen shared a few minutes ago during her testimony. People with disabilities rely upon those services in order to access employment, to enter the workforce, to stay in the workforce, to grow their earnings, and ultimately to grow their savings and to maintain participation in the mainstream economy. Over the last year, we know that employment for disabled people, we've calculated, is up 30 percent. That is a dramatic and important increase for people with disabilities.

With the right supports in place, people with disabilities are able to work in ways that support their bodies and minds. We are able to participate in the workplace. We want to participate in the workplace in ways that work for us, and ensuring that continued funding and increasing levels appropriately for Medicaid will guarantee that that can continue to happen.

We also know that now the ABLE program, which has allowed many more people with disabilities to continue benefiting from Medicaid, has resulted in \$2 billion—that's billion with a B, just to clarify, billion with a B - \$2 billion saved through ABLE. There are 187,000 able accounts currently open. That's an average of \$11,000 per account right now. Obviously, individual accounts might have greater or fewer assets in them.

However, we do know that these provisions allow people with disabilities to get jobs, to keep those jobs, to save money, build their wealth for the future, and have a financial future.

Ms. POO. I will just simply build on Counselor Brown's thoughts here and say, I would like for Congress to prioritize your legislation, the Better Care Better Jobs Act. A breakthrough in that legislation is the knitting together of investments in services and the workforce, which are truly interdependent investments. You cannot have more access to services without a strong workforce in place,

and without a strong workforce there is no foundation for home-and community-based services.

We were so grateful to have this legislation introduced, and the momentum that it has gained in the last few years is extraordinary, and I really hope that Congress will take this up, and in any case, we should not be entertaining cuts to Medicaid. 80 million people rely on Medicaid for healthcare and essential services.

Millions of families rely on Medicaid, home-and community-based services. If there are threats to Medicaid, lives will be at stake, and we cannot afford that in this country. It is not acceptable, and we just hope that this next Congress will protect Medicaid, and strengthen Medicaid, and invest in Medicaid home-and community-based services.

The CHAIRMAN. Well, Ai-Jen, I wanted to emphasize what you just said; both the importance of advancing home-and community-based services legislation, the Better Care Better Jobs Act. It's better that you said it first than I said it for the next Congress, the next administration.

I thought it was also noteworthy and significant as well as you emphasize not cutting Medicaid, which it would be in a word, catastrophic, for the country and really beyond catastrophic for the most vulnerable.

You also said on page two of your testimony, the American Rescue Plan Act resulted in over \$36 billion to expand access to Medicaid home-and community-based services and raise wages for direct care workers, and then you put in bold, all caps, all 50 states took this funding because of the extensive need for care across the country.

I emphasize those words from your testimony because this is no longer in the realm of theory. We have data now that every State has embraced this, at least to begin to erect a kind of foundation for home-and community-based services that does not exist in the United States of America.

This great country that we are doesn't allow the choice for an individual, either a senior or a person with a disability to make the choice to say; I want to have care in my home. I have a disability. I want to be able to stay in the community. I don't want to be consigned only to an institutional setting. A lot of great nursing homes out there, most do a really good job, but an American ought to have a choice about where they get their care, where they live. It's basic to our dignity and our sense of who we are.

I think it was noteworthy that the American Rescue Plan, which was not bipartisan, but when the dollars were available, all 50 states embraced it not because they had nothing else to do, or had some philosophical agreement with those of us who are advancing this idea, they embraced the dollars because their constituents, Democrats, Republicans, Independents, people they represent in these states are telling them, we want this. This is what we deserve as Americans.

I think any public official who just throws up their hands and says, "Oh, well, we can't do that. It's too complicated," is going to find out that there are going to be people coming through their front door to demand this, and they should demand it, and we

should, at the federal level, be instrumental in helping them. I went a little longer there. It's the last hearing, so.

Senator BRAUN.

Senator BRAUN. You are entitled to that, I think. Thank you. Mr. Orrell, when we put all the resources to significant issues like this, and in my opening statement talked about the general economy, which, you know, we've had record inflation over the last three to four years. The Federal Government has grown to like 25 percent of our GDP. It's never been 20 percent before, resources, all of them borrowed to kind of put us into those stats there, I'm curious, have more disabled individuals come into employment so we can see what's happened there. What can you tell us about—has it worked or have the negative consequences of higher inflation, higher debt—some would say a robust economy through government, but not in the real economy. What can we see with real stats there? Has it worked?

Mr. ORELL. I would say that it's very important in this to look across the entire federal budget. The resources going into disability programs can be very significant. Maybe \$450 billion between SSI, SSDI, VA, Medicare, and Medicaid. It's a lot of money. We are spending about \$4 trillion on regular Medicare, Medicaid, and the Affordable Care Act programs.

It gives us some sense of the proportions that need to be addressed. I don't think there's a one measure solution to the budget deficit. I think we've got a big problem across the federal budget, and there are certainly bigger targets than disability that we need to address, but disability needs to be part of the mix.

I would say for the long-term well-being of disabled people and the economy—or disabled people what they need most is a strong economy. This isn't an option. Like, it would be nice to have—it's important to have the programs, and it'd be nice to have a strong economy.

A strong economy is the most important protective factor for people with disabilities, because it creates the revenues that makes it possible to provide the services that people with disabilities need, and it pulls them into the workforce. It enhances their dignity as individuals to be able to access employment. A hot economy does that, it does that better than anything else we can do.

Senator BRAUN. Better than what government would be able to do through directing resources, even particularly at the problem?

Mr. ORELL. Let me say this, I have a son with autism who has benefited greatly from public services in our school system in Northern Virginia. He's now enrolled in a vocational training course run by the State of Virginia. I had a granddaughter, she passed away, who was severely disabled, and we needed round the clock nursing coverage for her. I do not diminish the importance of these programs at all. They do make a big contribution to the well-being of our citizens.

The question is, do we have people on these benefit programs that would be better off with accommodations and supports that would allow them to work? We need their work. This isn't strictly altruism. We have an extremely tight labor market. We need to get more out of that labor market.

Senator BRAUN. Then, has there been a measurement over the last four years? Have more disabled people come into the workforce significantly? Has it been flat or has it gone the other way?

Mr. ORELL. I would say, over the last decade, we've seen significant improvement in people working and disabled people moving into the workforce.

Senator BRAUN. Any observation over the last four years where we've had dramatic inflation and economy has been government-driven as opposed to private sector-driven?

Mr. ORELL. I would say the evidence is mixed. We have seen a reduction in the number of people on disability that was driven by some regulatory changes about how we assess disability. Some of that reduction was due to people aging out of disability programs, so, it's not exactly clear the answer to the question, but we do know wage inequality has declined because of very strong employment market.

We've got more people with disabilities in the workforce, and I think what that says to me is that a strong economy is the single most important aspect of what we need to be doing for people with disabilities.

Senator BRAUN. One other question. In terms of the responsibility between the Federal Government and states—I'm going back to set the agenda, run a State. Generally, they work with balanced budgets. What's your opinion of how much of the responsibility should be done here versus there, and which would be more effective and use the resources more efficiently?

Mr. ORELL. I'm a big believer across federal programming that we need to devolve as much responsibility and authority over these programs out of Washington into the states. The states have a much better handle on the needs of their communities, the needs of the individuals living in those communities. I think that they need to be in charge as much as possible in the administration of these programs. The Federal Government's main role here, I think is providing a baseline set of resources that is administered by the states, and so, across the board, this isn't just disability. I think in workforce programs, it's the same challenge. States, Governors, local business communities, they know what's needed, and they need to be empowered to make those decisions.

Senator BRAUN. Thank you.

The CHAIRMAN. Thank you, Ranking Member Braun. I turn next to Senator Warren.

Senator WARREN. Thank you, Mr. Chairman. Senator Casey has been a tireless champion for American families. As Chair of the Aging Committee, he has been right at the center of fights for rights for Americans with disabilities lowering the cost of childcare and elder care, and raising wages for workers.

Megan Lukowski, a caregiver and disability advocate from Philadelphia, put it this way, "Senator Bob Casey opened his eyes to our families and saw the needs of our children. He opened his ears and listened to our lived experience. He opened his heart and genuinely cared about improving our children's situation, and as Senator of Pennsylvania time and time again, he opened his mouth to fight for our kids' access to care and to their community.

It will always be scary sending a disabled child out into the world, but with Senator Casey representing us, we could rest assured, knowing that they had a champion in Washington." I ask that the statement regarding the chairman's work be entered in its entirety into the record.

The CHAIRMAN. Without objection.

Senator WARREN. Thank you. American families need Congress to continue building on Senator Casey's legacy, but instead, the big-ticket agenda item for Republicans next year is a \$4.5 trillion extension of the Trump tax cuts, mostly for billionaires and billionaire corporations.

Now, what could \$4.5 trillion buy us instead? Well, we could restore the expanded child tax credit and the child and dependent care tax credit that Senator Casey helped pass in the American Rescue Plan to put more money into the pockets of working families. We could make home care for seniors and people with disabilities more affordable, as Senator Casey has championed. We could pass paid leave for every worker so that no one has to choose between a paycheck or caring for a loved one who needs help, and we could guarantee affordable childcare for every family in America.

Now, I listened as Senator Braun and Mr. Orrell talk about how to build a strong economy, so, I want to pose that same question. I just want to do it slightly differently. Ms. Poo, you are president of the National Domestic Workers Alliance. That means that you represent two and a half million domestic workers. If we're going to spend \$4.5 trillion dollars, I just want to know which is the better investment in our economy overall. This is not about for individuals, it's just what's going to make the economy work better? Is it lowering cost for families and raising wages for care workers on the one hand, or another tax giveaway largely sucked up by millionaires, billionaires, and giant corporations? Which is going to promote our economy more?

Ms. POO. Senator Warren, thank you so much for that question. I should hope that if we are going to spend \$4.5 trillion, that we're going to spend it on the needs of everyday American families. The cost of care in this country is astronomical. Childcare for two children costs more than rent in every State In America, the lack of paid leave costs Americans \$22 billion annually, and the cost of aging and disability care at home costs between \$62,000 and \$280,000 per year.

Instead of more handouts to billionaires and corporations, we can afford to ensure every child has access to high quality early childhood education, every worker in the U.S. has paid leave. As you said, we can raise wages for hardworking American families. That seems like the better return on investment.

Senator WARREN. I very much appreciate your underscoring this point. You know, the reminder that when we raise wages for caregivers, that means there are more caregivers available. More people will go in, more people will stay in. More people will make this a part of their careers, and what does that mean? There are more people who have other jobs that will be able to go to those jobs?

You know, I think of this as the double investment.

Ms. POO. Yes.

Senator WARREN. The investment that is the right investment for those who need the care and the families that are struggling to give it, but also the investment if we want more workers in our economy, one of the ways we get more workers in our economy is to have care for those who need care at home.

President Trump and Republicans in Congress have been clear that their plans to pay for the next tax giveaway to billionaires and billionaire corporations is to slash investments that actually grow our economy and support these good jobs. They plan to cut programs like Social Security. They're planning higher taxes on everyday items that families buy like groceries and cash. Next year's tax fight will be an opportunity to show the American people whose side they are on; the side of billionaires who are clamoring for more handouts, or on the side of hardworking Americans.

Chairman Casey, I know which side you are on. I just want to say thank you for your leadership, for your determination, and for everything that you have done for American families. It is an honor to fight alongside you.

The CHAIRMAN. Senator Warren, thanks so much for your comments, and also for the great advocacy that you undertake every day on behalf of the people of the Commonwealth of Massachusetts, and the American people, and especially American families. I'm so grateful for your work, and we will miss working with you.

Senator WARREN. Thank you.

The CHAIRMAN. Senator Warnock.

Senator WARNOCK. Thank you so very much, Chair Casey. I just want to echo the sentiments of Senator Warren and so many others, and take this opportunity to thank you so very much for your fine leadership in the Senate and on this Committee. Certainly, on behalf of Pennsylvanians, but also on behalf of Georgians, on behalf of the American people you have been a dedicated public servant in the tradition of your family centering the most marginalized members of the human family, the disabled, the elderly, the poor.

Just the four-years that I've served on this Committee, you've improved access to healthcare, you've strengthened protections for seniors, you've centered people with disabilities so that all Americans can survive can thrive, and we can have an economy that, that serves the whole country, so, thank you so much, and I look forward to continuing the great work on this Committee.

Nearly 15 years after the passage of the Affordable Care Act, 10 states, including sadly my State of Georgia, have not fully expanded Medicaid. Georgia has the dubious distinction in fact of being the only State in the country that currently requires low-income folks to jump through bureaucratic paperwork hoops in order to satisfy work requirements to access Medicaid.

Let me underscore that. That they want you to jump through these bureaucratic hoops to get healthcare, rather than recognizing that a baseline of healthcare is necessary to have a strong workforce. It's been a drag on the Georgia economy to be sure. Ms. Poo, how do Medicaid work requirements, in your view, affect people with disabilities?

Ms. POO. Senator Warnock, Medicaid work requirements, in general, quite simply do not work. The vast majority of Medicaid enrollees are working.

Senator WARNOCK. Right.

Ms. POO. Period. The remaining enrollees are family caregivers, students, disabled people, who may not be working for very legitimate reasons, including lack of access to caregiving services.

Work requirements are also administratively so burdensome, as you referred to states spend millions of dollars to set up systems to manage work requirements. Meanwhile, disabled people are particularly harmed by Medicaid work requirements because of the lack of accessible formats for work reporting in State systems, barriers to receiving reasonable and accommodations in order to work employment discrimination, and the high burden of proof to qualify as disabled.

Instituting work requirements means disabled people, family caregivers, direct care workers who provide critical care, disabled people, and older adults caught in red tape, lose their health insurance, and suffer, all while costing State budgets millions in administrative costs that should simply just be going toward making sure people have healthcare.

Senator WARNOCK. I appreciate your clarifying the consequences of these political talking points that folks make, because that's what it is. It's not reality. It is talking points.

I'll give you another example from Georgia. There was a young woman whom I had the honor of meeting. Her name is Heather. Heather is a traveling nurse from Dalton, Georgia, and she falls in the Medicaid coverage gap that unfortunately we still have in Georgia. I brought her with me as my guest for the State of the Union address, and I've been dealing with addressing this Medicaid gap since long before I came to the Senate.

After experiencing a series of small strokes that left her unable to work full-time, Heather started the very lengthy process of applying for Social Security Disability Insurance, SSI, which will allow her to automatically qualify for Medicaid. While she waits for a decision on whether she meets the strict requirements of SSI, Heather, who is a nurse who dedicated her life to caring for patients, ironically, can't afford to pay for her own medical care out-of-pocket because she doesn't have enough to qualify subsidy for subsidies to buy private insurance.

That's a tragic irony. It's a woman who spent her life attending to other people's healthcare needs, and she's stuck in the healthcare gap in Georgia. Ms. Poo, should we be making it easier or harder for folks with disabilities for like Heather to access affordable healthcare, and why?

Ms. POO. Senator, we should always be making it easier for people to access healthcare. For millions of disabled people with high health needs, Medicaid is a critical lifeline to care that prevents unnecessary hospitalizations, improves health outcomes, and helps bring people who can work into the workforce.

People with disabilities cannot afford cuts to Medicaid, and let me be clear, that work requirements equate to massive cuts to the program that would lead to less services for healthcare and care in the home. In Georgia alone, more than 7,000 people are already on waiting lists for Medicaid, home-and community-based services. Services they depend on for their very basic needs. We have the opportunity to invest in Medicaid and ensure that more people can

have access to healthcare, and the aging and disability care in the community they deserve.

Senator WARNOCK. Just so it's clear to the folks who are listening, non-elderly adult caregivers, who make under 100 percent of the federal poverty level, are they eligible for Medicaid in Georgia?

Ms. POO. No, they're not.

Senator WARNOCK. Caregiving is not a qualifying activity for the work requirement. Is that correct?

Ms. POO. That is correct.

Senator WARNOCK. Thank you for your advocacy. Again, Senator Casey, thank you for your incredible work on this and so many other issues. I could say so much about Bob Casey, but it's better said really by his own constituents, and if he would just give me a moment as chair, the following testimonial is from Anna, a mother and an advocate from Hanover, Pennsylvania.

She said, "I brought my children to meet Senator Casey in his office in DC in the summer of 2017. I wanted him to hear our story. I wanted him to understand what Medicaid had done for our family, how it lifted us out of poverty and saved us from losing our home." She said, "I quickly learned that Senator Casey already had a deep understanding of the positive impacts of Medicaid. He listened intently to our story, and that day he became connected to our family. When speaking of Senator Casey, I always tell people," she said, "he's the real deal. He truly cares about his constituents. He remembers their names, he remembers their stories."

Please know that your absence in the Senate will be mourned by both the disabled and able-bodied people, not only of Pennsylvania, but of Georgia people all across the country. Thank you for representing us so well. Thank you for your service to all of us.

I ask that this statement regarding the chairman's work be entered, if the Chairman does not object—in its entirety, into the record.

The CHAIRMAN. Without objection. Thank you, Senator Warnock, for referencing a constituent of mine, so many of them that you've worked with and I've worked with in our states take on these battles, to be advocates, and sometimes against long odds, and to stop the kind of cuts that were presented in those days, but will be likely part of the dialog next year, so, I know you'll be in that fight. Thank you, Senator.

Senator WARNOCK. Thank you, sir.

The CHAIRMAN. Appreciate it. I just have a couple more questions. I wanted to get to a question earlier to Erin Willman about subminimum wage. Erin, you shared in your testimony how you started the White Cane Coffee Company because of lack of job opportunities that you and your brothers faced as people with disabilities. You made it a priority to pay your employees a fair wage and to provide high quality jobs.

Unfortunately, that's not the case for all employers. The Department of Labor has recently announced a proposed rule to phaseout subminimum wages to workers with disabilities, but we all know that more work needs to be done to make this goal a reality. I have bipartisan legislation to do that, and we're working even these last number of days of the year and of my time in the Senate to pass that.

Erin, I wanted to ask you, what advice would you give to employers, because you are one, and to people with disabilities about how to ensure full equitable access to both fair wages and high-quality jobs?

Ms. WILLMAN. Thank you, Senator Casey. I think that employers should really do their research to see what benefits they can find to be able to pay their employees a proper for wage. It is difficult out here for us, and so we are doing our best, and for the employees, they should know their worth, and know that what they put into the job, they will get out of it, especially if you find the job that does pay a livable wage.

The CHAIRMAN. Well, your testimony is especially significant and compelling because you see these issues from the perspective of someone who lives with a disability and also someone who has been an employer, and a successful employer, and an employer of people with disabilities, so, we're grateful for that perspective.

Mayor McDevitt, I wanted to ask you a question about the issues you raised about running for elected office which, which I have done not with the challenges and barriers that you faced, and I wanted to thank you for sharing your story. You've shared with me and with our colleagues the challenges you faced as a person with disabilities running for elected office, and the lack of funding for reasonable accommodations for elected officials with disabilities to perform their duties once they're elected.

You are the inspiration for a bill that I introduced called the Accessibility and Inclusion to Diversity Local Government Leadership Act, which you made reference to. However, there is a lot more work to do to ensure that people with disabilities are represented in all levels of office.

Mr. Mayor, as we look to the future, what can we do to help reduce barriers for people with disabilities to run for and serve in public office?

Mr. McDEVITT. Thank you, Senator Casey. As I mentioned the bill that you introduced, the AID Act, the Accessibility and Inclusion for Diversity Local Governance Leadership Act, would be a huge step in the right direction because it would remove the cost of accommodations for anyone who wishes to run or campaign today.

Now, for example, it feels like open season. Any issue can become politicized, so, by removing the cost of accommodations from the discussion, we can focus on the person's abilities, their ability to represent people in their community. One wonderful example of this in the past with Senator Fetterman's election, people questioned his ability to represent the State, the Commonwealth of Pennsylvania, because the accommodations became an issue that should not have been an issue. It should not have been for discussion. Local governments are probably the most accessible place for people to start in terms of the political field, so, your Act would ensure that all politicians of both parties would be welcome to the table, and that would be a key first step.

The CHAIRMAN. Thank you very much, and thanks for being both an advocate and a model for those who would seek to run for public office with a disability. We're grateful for that, and, of course, that inspiration has spread, I think, at least across our State, and I'm

sure well beyond. Because, of course, Erin ran for State representative and we're grateful that she took on that challenge, and Erin, if I know anything about politics, you can run again, so, don't let that be your last election after you make a lot of money in that coffee company.

I wanted to close. Ai-Jen, I wanted to see if there's anything else you wanted to add to the record, or anyone else for that matter. If you have anything else you wanted, you can certainly add written statements to the record that would amplify or, or, or add to your testimony.

Ms. POO. Mr. Chairman, before I end my time, I would like to take a moment to read a message from one of your Pennsylvania constituents. It's a statement from Dr. Amy Houtrow, physician and disability advocate from Pittsburgh, Pennsylvania, the city where I was born, actually.

"In the disability justice movement, you often hear the rallying cry, nothing about us without us. Senator Casey has taken this to heart, and brings people with disabilities to the table. Make sure they have a seat at that table, and a voice that is heard and respected. In a world where people with disabilities are marginalized, disregarded, dehumanized, and discarded, Senator Casey has used his authority, time, and efforts to elevate issues faced by disabled people."

Pennsylvanians, especially disabled Pennsylvanians, and all disabled Americans, have a champion in Senator Casey. I know that even after his Senate term ends, we still will.

I ask that the statement regarding the chairman's work be entered in its entirety into the record.

The CHAIRMAN. Without objection.

Again, Ai-Jen, thank you for reading that into the record in this last hearing. I'm reminded, I was sitting here in an Aging Committee hearing back about, gosh, it must be a decade ago now. More than a decade, 12 years ago. The chairman of the Aging Committee then was Herb Kohl from Wisconsin, and Herb was a pretty low-key person, and apparently before the hearing, he instructed everyone not to make statements that would be laudatory of the chairman, and they did it anyway.

I know now I know what Herb was feeling, what he was thinking at that moment, but I'm so grateful for those statements about my service, and in particular, the service of those who have served with me, and my staff, and for purposes of today, especially the aging Committee staff, which I'll make reference to in a moment, but because of time, we do have to wrap up, and I will there may be more questions for the record that we will submit for our witnesses, but I do want to start by thanking our witnesses for their, their testimony and the, the unique expertise that they bring to a hearing like this. Both expertise that has its origin in their academic work, as advocates, or researchers, or experts in the field, but also that they bring to bear their own personal experience when they come to testify at this hearing and hearings like that we've had in the Aging Committee, so, we're grateful for that. We're grateful for their testimony.

We know that based upon what we've heard today, there's a lot more work that must be done to protect the lives of and the rights

of individuals with disabilities. Whether it's living wages or wealth building access to higher education, accessible technology, home- and community-based services, and accessibility to ensure civic participation, these are just a few, not an exhaustive list of the many issues that people with disabilities face every day.

As Ai-Jen Poo just made reference to, there's a constant refrain over the years from the disability community; Nothing about us, without us. My job as chairman of this Committee has never been to speak on behalf of seniors, or on behalf of people with disabilities, or the disability community. My job has been instead to be an advocate, as best I could do it, to be an advocate and to work as chairman to raise up the voices of both older Americans and people with disabilities.

As I said in my opening statement, and we've heard from our witnesses, this work is not done. There's a lot more work to do, and we all have an obligation to do that work. Elected officials play a role. Advocates play a role. The business community plays a role. Every segment of society, every sector of our economy has a role to play in lifting up and affirming the rights of and the dignity of, and the contributions of people with disabilities, so we've got to continue to advance disability policy that makes it possible for people with disabilities to be fully engaged Americans to lead full lives, to enjoy the full measure of American freedom.

I want to express my gratitude, in particular, for the work we've done, to the Aging Committee staff, led by our staff director, Lizzie Letter, who's over my left shoulder, and Michael Gamal McCormick, who's right over my right, and your left with that cool green tie on. Michael, and Lizzie, and their team have been extraordinary advocates in their own right, as well as Aging Committee staffers; working on hearings, working on research and investigations, and other work on behalf of seniors and on behalf of people with disabilities.

I will, without objection, enter into the record a list of Aging Committee staff members who are members of the staff as of December 2024, as we conclude this 118th Congress.

I also note for the record that we have a former Aging Committee Staff Director, Kate Mevis, who's in the audience sitting next to our incomparable Chief of Staff, Kristen Gentile, for their work. Kristen, presently, and for over many years, and Kate, when she was a member of the Aging Committee staff and leading that staff in those years, and without objection ranking member Braun's closing State will be made part of the hearing record.

Again, I've enjoyed working with Ranking Member Braun, and wish him well in his next assignment in public service, and once again, I want to thank the witnesses, and frankly, by extension, all the witnesses who have appeared before our Committee over the years for their contributions.

I have 35 statements for the record, some of which we heard today from Pennsylvania constituents that I'll enter into the record without objection.

If any Senators have additional questions for the witnesses or statements to be added, the hearing record will be kept open until next Wednesday, December the 18th.

Let me conclude with just a couple of thoughts about disability policy. We know, as I made reference to earlier, the Americans with Disabilities Act passed in 1990, set four goals for people with disabilities. Number one, economic security. Number two, full participation. Number three, independent living, and number four, equal opportunity.

We've made great strides on all four, but the full realization of those four goals still lies ahead of us. Not just ahead of us, for those who will be serving in Congress, but lies ahead of us as Americans. We all play a role in advancing those goals.

I leave my chairmanship of this Committee with a charge for everyone to continue to build on that progress and to ultimately achieve those goals. It's been an honor

to serve as chair of this Special Committee on Aging. It's been an honor to serve in the Senate these 18 years.

I want to thank you-all for participating today. This concludes our hearing. Thank you.

[Whereupon, at 11:47 a.m., the hearing was adjourned.]

APPENDIX

Prepared Witness Statements

U.S. SENATE SPECIAL COMMITTEE ON AGING
 "EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
 DECEMBER 12, 2024
 PREPARED WITNESS STATEMENT
Brent Orrell

Chairman Casey, Ranking Member Braun and members of the committee, thank you for the opportunity to testify on the critical issues facing aging and disabled members of the American workforce. I'd like to frame my remarks on this topic in two different but interrelated dimensions of concern: the practical demands of the American economy and the moral requirements of American society.

The largest single factor shaping the nation's economic future is demographics. Like all developed countries, America's population growth is slowing and, as a result, it is also aging. In 1960, the fertility rate in the U.S. was 3.6 children per woman. Today that figure has fallen to 1.6 children per woman. Over the same period, the median age has risen from 29.5 years to 38.9 years. Between 2000 and 2005, our working-age population grew by 12 million workers; that is in stark contrast to the more recent period between 2017 and 2022, in which our workforce grew by just 1.7 million.

Demographics are the chief driver of economic growth and living standards. Demographically older countries work less, buy less, consume fewer non-health related services, and are generally less economically dynamic. Our own country is not exempt from these realities. While we cannot quickly produce more people, we can do more to engage economically and socially marginalized populations-older workers, individuals with physical and cognitive disabilities, people with criminal records, and others-to help sustain and maximize economic growth. From the standpoints of worker shortages and economic dynamism, we literally do not have a single person to waste.

This brings us to the moral dimension. Being an American means believing in the intrinsic dignity and worth of each individual. Work is one of the most important ways we have to express and develop that dignity. Free markets allow us to align our interests, knowledge and skills to the needs of the broader economy and our fellow citizens. This need for recognition, connection, and community, and the satisfactions of contributing to the larger whole, is just as essential to older and disabled Americans as it is to anyone else.

If we fail to recognize, understand, and support the dignity-reciprocity dynamic that work enables, we are not just hobbling ourselves economically, we are failing to honor the nation's most important idea: that every human being is entitled to equality and dignity. To do well economically, we must also do good morally, paying special attention to those like older and disabled workers, who might otherwise find themselves left behind in the race of life.

Workforce Inclusion: Dignity and Opportunity for All

How are we doing in honoring our commitments to older and disabled workers?

The percentage of Americans aged 65 and older who are working or actively seeking work is steadily rising, with 19.2 percent now participating in the labor force. While this may seem modest, it reflects a significant shift: in 2000, only 25 percent of post-retirement-age seniors had jobs, compared to 32 percent today. The Bureau of Labor Statistics projects that by 2032, 8.6 percent of the U.S. labor force will be composed of older workers, up from 6.6 percent in 2022. For the reasons I outlined, we will need their contributions. Better health and longer lives are making that higher level of participation possible.

The labor market participation of individuals with disabilities has also seen notable improvements, although significant disparities remain. In 2023, 22.5 percent of people with disabilities were employed-the highest rate since comparable data collection began in 2008. By comparison, however, this rate is still about one-third that of workers without disabilities. Similarly, the unemployment rate for individuals with disabilities -people who have lost jobs and are actively seeking work -is double that for the general population.

These data underscore the barriers that many workers with disabilities face in accessing employment opportunities. These can include physical limitations or systemic disadvantages like bias or lack of accommodations that would make it possible for them to work. Even among workers with disabilities who do have jobs, many are unable to find full-time jobs that provide benefits like health insurance and re-

tirement. About half of all people with disabilities are also over age 65 further magnifying the barriers they face in seeking and finding work.

Technology's Role in Workforce Inclusion

Technology has added considerably to the "tool-box" that enables employment for workers with disabilities. Advances in artificial intelligence (AI), automation, and assistive technologies are opening new pathways for individuals traditionally excluded from the workforce.

Technologies such as screen readers, voice recognition software, and AI-powered communication tools can remove barriers to employment. These innovations enable individuals to perform tasks that were once inaccessible, leveling the playing field and expanding opportunities. Similarly, the growing sophistication of technologies like robotic exoskeletons and other assistive devices can enhance mobility for those with physical disabilities, allowing them to engage in previously out of reach occupations.

For older adults, technology offers opportunities to remain active in the workforce by mitigating physical or cognitive limitations. AI-driven tools like large language models and automation systems can simplify complex tasks, while telework platforms and collaboration software allow older workers to contribute to the economy without leaving their homes. Moreover, technologies that facilitate lifelong learning—such as online education platforms and virtual reality training simulations—can help older workers acquire new skills and adapt to evolving job demands.

The promise of technology will not be realized without intentional design and implementation. Policymakers must ensure that new technologies are accessible and affordable for all workers. One way of achieving this is to increase tax incentives to businesses that undertake redesign of their workplaces and job requirements to make them friendlier to those facing limitations. A similar approach could be used to encourage business investment in employee training for those with and without disabilities. Partnerships between government, industry, and educational institutions can help develop inclusive technologies while equipping workers with the skills needed to use them effectively.

At AEI, our scholars are engaged in a variety of research efforts looking at the impact of AI and other emerging technologies on education, training, and work as we seek ways to fulfill our mission of promoting opportunity for those at the periphery of American society. This research will undoubtedly reveal other ways public policy can help older and disabled Americans make their invaluable contributions to our society and economy.

The Path Forward

To build a more inclusive and dynamic workforce, we must take a holistic approach that combines policy innovation, technological advancement, and cultural change. I offer three recommendations for your consideration:

1. **Promote Inclusive Employment Practices:** Encourage businesses to adopt flexible work arrangements, provide reasonable accommodations, and foster inclusive workplace cultures. Public recognition programs and tax incentives can reward employers who lead in this area.

2. **Invest in Education and Training:** Expand access to lifelong learning programs that enable older adults and people with disabilities to gain new skills. Targeted funding for community colleges, workforce development initiatives, and vocational rehabilitation programs can help bridge skill and training gaps.

3. **Leverage Technology for Inclusion:** Support research and development of assistive technologies and ensure that federal job training programs prioritize inclusive tech solutions for the workforce. Expanding access to broadband and other digital tools are key to improving access to work for disadvantaged groups.

In closing, the issues we face—a dynamic economy that needs workers and demographic changes that are limiting the number of new workers available—are formidable, but not insurmountable. By fostering workforce inclusion for older and disabled Americans, we not only address economic challenges but also reaffirm our commitment to the dignity and potential of every American. Together, we can build a labor market that reflects our values and strengthens our economy.

Thank you for your time, and I look forward to answering your questions.

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
PREPARED WITNESS STATEMENT
Erin Willman

Hello, I am Erin Willman. I am the founder and CEO of White Cane Coffee, and I would like to thank Chairman Casey and Ranking Member Braun, along with the rest of the members of the Aging Committee for inviting me to speak on subjects that both I and many in the disabled community face.

A lot has happened since I was here in February. I have received an incredible number of calls and emails from disabled persons and organizations that assist the blind and disabled. The common theme of those messages is that things are actually changing. We are not yet where we need to be when it comes to disability access and acceptance, but we are getting there. It brings me great joy when I hear of disabled people in my community getting good paying jobs and not being relegated to sheltered workshops for less than minimum wage.

A few weeks ago, an engineer from a large manufacturer in our county, visited our coffee factory to see how we adapted our workspaces and machinery to accommodate our employees. He honestly wants his company to be inclusive. I consider this as a huge step forward. On a side note, I had the honor to run for PA State Representative for District 65. Even though I lost the election, I found that the majority of people I met were accepting of me as a viable candidate. The best part of the experience was having younger people come up to me and tell me that because of my running for office, they too now feel that they can also create change in their community in both large and small ways.

Today I would like to talk about accessible education and how it can be bettered with the RISE Act. People ask me all the time if I went to college. The answer I am sorry to say is "No." Despite the fact that I graduated high school at the age of 15, I felt wholly unprepared for the challenges that my disability would bring me in a college setting. However, my hope is that others in the disabled community won't feel that trepidation when they seek out higher education, but I recognize that there are things that need to be changed for that to happen.

At this time, people with disabilities who wish to go to college and need accommodations to be successful have to prove that they are disabled through costly testing, even if they were born with a disability or have previous documentation from when they were in high school.

I remember how nerve-wracking it was for those in my life who were heading off to college. I can't imagine putting more stress on a person with a disability because they must prove their disability to get the support they need to thrive. If a person already has documentation that they are disabled that should be sufficient. I don't believe that any prospective student who somehow miraculously became able bodied would try to ask for the same assistance they had before when they were disabled.

While proving that a person has a disability is disheartening enough, there is also the issue that many schools make it difficult to find out what sort of assistance and accommodations are available to disabled students. When looking into what college a student wants to attend, they have to comb through websites, visit the campus, and even, in some cases, contact the administration personally just to find out if the school has the accommodations that they would need to access the education offered by the college. If one school does not have the accommodations a particular student needs, the student will have to repeat the search process as many times as needed until they can find a school that is suitable. Not only can this process be stressful, it can also be so disheartening as to possibly turn them away from the idea of going to college at all. It doesn't have to be this way though. If schools were upfront and transparent about what accommodations are available the stress of finding the right school would be lessened significantly, making the transition into higher education easier.

Now I believe it is time to give the spotlight to our educators. We have all, at one point in our lives, had a teacher who has inspired and helped us find our path in life, so, I believe that they should have help to continue that work on a wider scale. It is an unfortunate truth that many teachers do not have the training that they need to accommodate a student with a disability. However, under the RISE Act this is a problem with an easy solution. The RISE Act would allocate funds to college administrations so that their faculty has the tools and know how to be able to teach all of their students, so they are able to thrive in their classroom. By edu-

cating our educators, our colleges can be a place where everyone can succeed no matter what.

I have always been extremely passionate about education. I believe that it can open doors and build bridges. It can lead to good jobs and a better life. Education expands a person's opportunities in life. It's why I work so closely with many schools for the disabled, so those students can create a brighter, more inclusive future. America is known as the land of opportunity. By implementing the RISE Act many disabled people across the nation will have the opportunity to seek out higher education without the worry that they would not belong. Something as simple as that would change their lives. If you change one life you change the world. It is time to change the world.

U.S. SENATE SPECIAL COMMITTEE ON AGING
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 DECEMBER 12, 2024
 PREPARED WITNESS STATEMENT
Lydia Brown

My name is Lydia Xinzhen Zhangsun Brown and I am the director of public policy at National Disability Institute as well as a proudly disabled advocate. Thank you for the opportunity to provide testimony before the Committee today.

Disabled people represent at least 20 percent of the U.S. population or more than 65 million people, although the real number is likely higher than current surveys indicate, including people who have newly acquired disabilities due to long COVID.¹ Our community faces deep economic disparities with poverty² and unemployment³ rates for people with disabilities about twice those of nondisabled people along with higher rates of homelessness⁴ and food insecurity.⁵

- According to our research with the Financial Health Network, disabled people are more than twice as likely to be financially vulnerable as nondisabled people.⁶
- Only 51% of working-age disabled adults are confident they can pay their bills on time and 46% of disabled adults carry more debt than they can manage.⁷
- Fewer women with disabilities, disabled people of color, and LGBTQ+ people with disabilities are financially healthy than people with disabilities who are men, white, or non-LGBTQ+.⁸

¹See Bonnielin K. Swenor, "A Need For Disability Data Justice," Health Affairs, Aug. 22, 2022, <https://www.healthaffairs.org/content/forefront/need-disability-data-justice?ref=disabilitydebrief.org>; Centers for Disease Control & Prevention, Disability and Health Data System, "Disability Impacts All of Us," Jul. 2024, <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html> (estimating close to 28%). But see U.S. Census Bureau, 2022 American Community Survey (ACS) Content Test report for Disability, Nov. 13, 2023, <https://www.census.gov/content/dam/Census/library/working-papers/2023/acs/2023—Steinweg—01.pdf> (noting current Census estimates at only 13.9% of the population and estimating drop to 8.1% if the Census altered its measurement of disability).

²Office of Disability Employment Policy, Spotlight on Women with Disabilities, U.S. Department of Labor, Mar. 2021, <https://www.dol.gov/sites/dolgov/files/ODEP/pdf/Spotlight-on-Women-with-Disabilities-March-2021.pdf>, based on 2019 data by gender, disability status, and using the official poverty measure for means-tested program eligibility and 2020 data from the Current Population Survey. 2020 Annual Social and Economic Supplement, U.S. Census Bureau, <https://www.dol.gov/sites/dolgov/files/ODEP/pdf/Spotlight-on-Women-with-Disabilities-March-2021.pdf> (as analyzed by NDI with Asset Funders Network)

³Bureau of Labor Statistics, U.S. Department of Labor, Persons with a Disability: Labor Force Characteristics-2022, Press Release, Feb. 23, 2023, <https://www.bls.gov/news.release/pdf/disabl.pdf>.

⁴Jaboa Lake, Valerie Novack, & Mia Ives-Ruble, "Recognizing and Addressing Housing Insecurity for Disabled Renters," Center for American Progress, May 27, 2021, <https://www.americanprogress.org/article/recognizing-addressing-housing-insecurity-disabled-renters>; Pooja Paode (2020), "Housing for Adults with Autism And/or Intellectual and Developmental Disabilities: Shortcomings of Federal Programs," Daniel Jordan Fiddle Foundation Center for Public Policy. <https://www.researchgate.net/profile/Pooja-Paode/publication/346041472—Housing—for—Adults—with—Autism—and—or—Intellectual—and—Developmental—Disabilities—Shortcomings—of—Federal—Programs/links/5fb8202c92851c933f47f1eb/Housing-for-Adults-with-Autism-and-or-Intellectual-and-Developmental-Disabilities-Shortcomings-of-Federal-Programs.pdf>.

⁵Coleman-Jensen, A. & Nord, N. (2013). Disability is an Important Risk Factor for Food Insecurity, United States Department of Agriculture, Economic Research Service. <http://www.ers.usda.gov/amber-waves/2013-may/disability-is-an-important-risk-factor-for-food-insecurity.aspx#.Vi3GrPkrKUK>.

⁶Andrew Warren, Wanjira Chege, Meghan Greene, & Lisa Berdie (August 2023), RESEARCH PAPER: THE FINANCIAL HEALTH OF PEOPLE WITH DISABILITIES: KEY OBSTACLES AND OPPORTUNITIES, Financial Health Network, National Disability Institute, The Harkin Institute, & Principal Foundation, <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2023/09/the-financial-health-of-people-with-disabilities-report-final-0923.pdf> at 15.

⁷Id. at 6.

⁸Id. See generally also, Nanette Goodman, Michael Morris, Kelvin Boston, National Disability Institute, FINANCIAL INEQUALITY: DISABILITY, RACE AND POVERTY IN AMERICA, <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/02/disability-race-poverty-in-america.pdf>.

- Over 30% of disabled households have an income below \$15,000 - a rate 5.6 times higher than for households without a disability - and those numbers are substantially higher for Latinx and Black households with disabilities.⁹

These economic disparities in earnings, savings, banking, and wealth building are exacerbated for the many people with disabilities who rely on means-tested public benefits to survive. Many disabled people rely on Medicaid as the sole provider of long-term supports and services - help with eating, taking meds, getting dressed, and even positioning their bodies - that can keep people in their own homes instead of nursing homes and institutions, as well as enable people to enter and remain in the mainstream workforce. Eligibility for Medicaid, however, is tied to eligibility for Supplemental Security Income or SSI. A beneficiary is prohibited from having more than \$2,000 in countable assets if single and \$3,000 between both spouses if married - asset limits that were last updated in 1989.

A person with a disability who wants to work and is able to work for any amount of hours is precluded from seeking the same array of opportunities as a nondisabled person if that disabled person relies on Medicaid-funded support to live at home or get to work. Some disabled people turn down promotions, hours increases and raises in order to maintain eligibility for Medicaid because accepting the increased wages would not cover the gap if they lost their benefits. These asset limits can force people to choose between going without necessary medication or paying their light bills, or buying enough food, or making rent. An emergency bill of \$2,100 - a modest amount for some hospital stays - could leave a disabled person on SSI with no savings at all and snowballing consequences of carrying the debt.

Ten years ago, Senator Casey's leadership in introducing and passing The ABLE Act changed the game. People whose disabilities began before age 26 can now access a savings vehicle that can conserve up to \$100,000 total without their savings counting against them in determining eligibility for SSI and Medicaid. Money in an ABLE account can be used for a wide range of qualified disability expenses, including otherwise unaffordable assistive technology and health care, as well as educational and employment related costs. For many disabled people on Medicaid, an ABLE account is also their only available means to save for retirement.

In recent years, NDI also championed Senator Casey's leadership in passing multiple improvements to ABLE, including the ABLE Age Adjustment Act, which widened ABLE eligibility to people whose disabilities began by the age of 46, a provision that comes into effect a year from now and will ensure eligibility for more than 6.2 million additional people with disabilities including one million veterans.

As we look forward to the future of the ABLE program, we know there are many opportunities for further growth and improvement, especially to benefit the most impoverished people with disabilities, who may not be able to make contributions to an ABLE account, and disabled people who are working and earning enough to make contributions in excess of the current \$18,000 annual limit.

Members of the Senate are currently considering a range of improvements for the ABLE program, all of which would greatly increase financial capability for people with disabilities. The ABLE Direct Deposit Act and The ABLE Employment Flexibility Act would codify common-sense improvements like allowing direct deposits and employer retirement contributions into an ABLE account. The ABLE Awareness Act, The ABLE Tomorrow Act, and The ENABLE Act would collectively support engagement and education efforts around ABLE to increase enrollment for eligible beneficiaries, protect against Medicaid clawbacks after a beneficiary's death, and allow one-time lump sum contributions over the annual limit. Language in these bills would also permanently adopt provisions allowing additional contributions to ABLE accounts for working people with disabilities, a saver's credit for ABLE contributions, and rollovers from 529 education savings accounts to ABLE accounts.

Opportunities remain for increasing economic opportunity and participation for people with disabilities, who deserve to have the full range of financial choices and freedom as people without disabilities. Future legislative efforts can expand eligibility to more people with disabilities, protect rights of youth in the foster system and adults under guardianship, and increase disabled people's ability to save for retirement on par with nondisabled people. I believe in a future where all people - both disabled and nondisabled - can be assured of basic economic security and opportunity. This includes a future in which disabled workers can save for retirement

⁹Ramonia Rochester, Elizabeth Jennings, Joe Antolin, & Christi Baker (June 2023), ADVANCING ECONOMIC JUSTICE FOR PEOPLE WITH DISABILITIES, National Disability Institute & Asset Funders Network, <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2023/06/afn—2023—persons-with-disabilities—brief.pdf> at 14.

on par with nondisabled workers and disabled people have no ceiling on the amount of income they can earn and savings they can build - just like everyone else.

Thank you again for the opportunity to speak before this Committee today. I urge you to continue championing policies that advance equity, financial inclusion, and economic opportunity for people with disabilities. Together, we can create a society where all people have the resources and opportunities to achieve financial stability and economic security.

U.S. SENATE SPECIAL COMMITTEE ON AGING
 "EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
 DECEMBER 12, 2024
 PREPARED WITNESS STATEMENT
Mayor Neil McDevitt

As a resident of the Commonwealth of Pennsylvania, I'm heartened to sit before Senators Casey and Fetterman on this special day. Ranking Member Braun and other members of the Committee, thank you for welcoming me today.

I sit before you today as the Mayor of North Wales Borough, an amazing community of 3,400 residents in Montgomery County just outside of Philadelphia. That may not be remarkable in itself - there are, after all, over 519,000 elected officials in the United States today.¹ I am unique in that I am, as far as we're able to tell, the first Deaf person to be elected to the office of Mayor that uses American Sign Language as their primary means of communication.

Concurrently with my role as Mayor, I am also the Executive Director of the Deaf-Hearing Communication Centre, a regional nonprofit organization providing critical services to the Deaf, hard of hearing, and DeafBlind community members in the Philadelphia region. I previously served with the Federal Emergency Management Agency (FEMA) in their Office of Disability Integration and Coordination. I also worked at Telecommunications for the Deaf and Hard of Hearing Inc. (TDI) managing their emergency management grants. I also served my community as a volunteer firefighter for eight years, as one of the few disabled individuals nationally certified to do interior firefighting. I am also a proud alum of Gallaudet University right here in Washington, DC.

As an elected official who uses American Sign Language and the first one in the Commonwealth of Pennsylvania - we find out very quickly what barriers exist for us in doing our jobs effectively.

Deaf individuals like myself represent a unique aspect of the disabled community, in that the accommodations that make our jobs possible are operational costs. For most disability accommodations, the cost to retrofit a building or provide a device to make it accessible to individuals with disabilities is a capital cost that can be amortized over the lifetime of the facility/device.

For me, the cost of an interpreter is essentially a direct charge against the profit/loss ledger, or in the parlance of local government, represents a cost that taxpayer dollars cover.

In a tiny community like North Wales, I'm blessed that the Borough Council and Borough Manager wisely had funds set aside in their budgets long before I was elected to ensure accommodations for people with disabilities. I know that this is fairly unique to small communities across the United States. The sad truth is that I don't have enough funds available to cover all of my interpreting needs and I need to pick and choose where I spend those funds.

Senator Casey, I shared the challenges I had with you and your colleagues. In your research, you also found another barrier that exists for people with disabilities that want to get involved in politics. That is, if a person with a disability simply runs for any office (paid, barely paid, or unpaid) - they can lose their Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) income, even if they don't raise any money or they lose their election.

In two separate Congressional sessions, Senator Casey introduced two bills. The "Removing Access Barriers to Running for Elected Office for People with Disabilities Act" would address the discriminatory language in the Social Security Act that penalized people with disabilities for running for office (S.3747/HR.7351).²

The second was "The AID (Accessibility and Inclusion to Diversify) Local Government Leadership Act of 2024" to address my challenge, that is, for small communities like North Wales Borough, it would establish a grant to reimburse those municipalities for accommodation expenses they incur for any elected and appointed officials with disabilities (S.3749/HR.7350).³

These bills are a critical step towards addressing a glaring gap in the demographics of our elected officials. Out of the 519,000+ elected officials across the coun-

¹ <https://poliengine.com/blog/how-many-politicians-are-there-in-the-us>

² <https://www.aging.senate.gov/imo/media/doc/removing-access-barriers-to-elected-office-one-pager.pdf>

³ <https://www.aging.senate.gov/imo/media/doc/aid-local-government-leadership-one-pager.pdf>

try, I am personally aware of only five who use American Sign Language nationally today. If we extrapolated the total number of users of American Sign Language⁴ nationally today and applied that to total elected officials, we should have over 1,550 elected officials using American Sign Language.

Extending that further - current estimates say that 10% of all elected officials have a disability of some type,⁵ but 28.7% of the population has a disability.⁶ The unfortunate conclusion is that our elected officials are not representative of the people they serve.

In the recent Presidential campaign, the Democratic candidate spent over \$35,000 on American Sign Language interpreting expenses while the Republican candidate spent nothing.⁷ In fact, during President-elect Trump's first term, the National Association of the Deaf had to bring lawsuits to require the administration to provide ASL interpreters.⁸

The reality is that the Americans with Disabilities Act is the last great civil rights bill that was passed with true bipartisan support. As I said during my remarks at the White House's Disability Pride event a few months ago - "I woke up one morning with rights I did not go to bed with. The ADA made millions of Americans first-class citizens in our own communities overnight."⁹

In the 34 years since the passage of the ADA, our political will toward safeguarding these vital human and civil rights have weakened significantly. I call on leadership and Senators from both parties to recommit to protecting these vital rights and services for millions of Americans. I ask you to look beyond the rhetoric of soundbite politics, and listen carefully to the people who would actually be affected by the policies that have been suggested or proposed by members of the incoming administration.

The next Congress can take positive and proactive steps toward ensuring the civil and human rights of people with disabilities stand fast. First - the passage of Senator Casey's bills, "Removing Access Barriers to Running for Elected Office for People with Disabilities Act" and "AID (Accessibility and Inclusion to Diversify) Local Government Leadership Act" would be an excellent first step toward ensuring that our elected officials are truly representative of the communities they serve.

Recognizing that when we remove all barriers to participation, people with disabilities are able to fully engage with the communities they live in. This means making it easier for people to vote, making it easier for them to run for elected office, and to volunteer for their small-town boards and commissions.

Congress must also ensure that the United States Department of Justice continues to work closely with counties and municipalities to ensure they are in compliance with civil rights statutes. That often means paying close attention to the accessibility of polling sites. The incoming administration's record in turning back the Department's civil rights focus and defunding their work is significant cause for concern.

Senator Casey, you have been a steadfast ally of North Wales Borough, the Commonwealth of Pennsylvania, and millions of disabled and Deaf Americans. We owe you a debt that can never be repaid. Thank you.

⁴ <https://gallaudet.edu/wp-content/uploads/gcloud/gal-media/Documents/Research-Support-and-International-Affairs/ASL—Users.pdf>

⁵ <https://disnetwork.org/the-lack-of-politicians-with-disabilities-is-a-systemic-issue/>

⁶ <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

⁷ https://open.substack.com/pub/heathercoxrichardson/p/october-23-2024?selection=6bc53a2b-9a8e-45c4-a89b-ca4e1015bfb8&utm_campaign=post-share-selection&utm_medium=web

⁸ <https://www.nad.org/2020/09/23/historic-win-white-house-ordered-to-provide-sign-language-interpreters-for-covid-19-briefings/>

⁹ <https://www.youtube.com/watch?v=cbNDDVxMgME>

U.S. Senate Special Committee on Aging
"Empowering People with Disabilities to Live, Work, Learn, and Thrive"
December 12, 2024
Prepared Witness Statement
Ai-jen Poo

Chairman Casey, Ranking Member Braun, and Members of the Committee, thank you for the opportunity to testify today. I want to thank Senator Casey for the invitation to speak at this hearing, as well as the full committee for holding this hearing on empowering people with disabilities. I'm grateful for the opportunity to reflect on the successes of the 118th Congress and examine the future opportunities and challenges which lie ahead. My name is Ai-jen Poo. I am the President of the National Domestic Workers Alliance (NDWA) and Executive Director of Caring Across Generations.

Founded in 2007, NDWA works to raise wages and strengthen industry standards toward economic security, respect, and workplace dignity for 2.2 million domestic workers in the U.S. NDWA represents more than 395,000 nannies, house cleaners and home care workers in all 50 states, with a network of over 70 local chapters and affiliate organizations.

Founded in 2011, Caring Across Generations works on behalf of family caregivers, care workers, disabled people, and seniors to change the way we support and value caregiving in the culture and policies of the United States – from aging and disability care, to childcare, to paid family and medical leave, and good jobs for care workers.

Together, NDWA and Caring Across Generations have worked for over a decade to bring attention to the growing need for investments in the care economy and the urgency of transforming care jobs into good jobs with family-sustaining wages and benefits. We lead Care Can't Wait, a national coalition committed to building a comprehensive care infrastructure that guarantees affordable care for all who need it, lowers costs for family caregivers, and creates good jobs for all care workers.

I represent both family caregivers and paid care workers, constituencies that have historically been neglected by the federal government, even as their labor provides critical support for disabled people and older adults within a broken system. Unpaid care work, two-thirds of which is done by women, disproportionately by Black and Asian women and Latinas, is worth more than 1 trillion dollars.¹ Most people would prefer to live and age in

¹Jessica Mason, Katherine Gallagher Robbins, "Americans' Unpaid Caregiving is Worth More than \$1 Trillion Annually – and Women are Doing Two-Thirds of The Work" National Partnership for Women & Families, June 27, 2024 <https://nationalpartnership.org/americans-unpaid-caregiving-worth-1-trillion-annually-women-two-thirds-work/>

their own homes and communities, but today more than 710,000 older adults and disabled people remain on waiting lists for Medicaid home and community-based services, deprived of essential, life-saving care.^{2,3}

Federal dollars, primarily Medicaid, not Medicare, pay for the vast majority of long-term care, including wages for workers who provide these services.⁴ Despite the immense need for people to care for our aging and disabled loved ones, these workers are also among the most underpaid. Direct care workers earn an average of just \$25,000 per year.⁵ These workers are less likely to receive paid family and medical leave and nearly half rely on public assistance such as Medicaid, food stamps, and other forms of cash assistance to make ends meet.⁶ The low pay and lack of benefits means that many workers are forced to leave the field, increasing training and turnover costs for employers, and diminishing the quality and consistency of care for families, older adults, and disabled people in need.^{7,8} Ensuring family sustaining wages and good job quality is essential to sustain the care workforce we need in our economy and in our communities.

Our country has taken strides to address these issues. In the last three years, we were able to make advancements for family caregivers, aging adults, disabled people and care workers. The American Rescue Plan Act, with the leadership of Senator Casey, resulted in over \$36 billion to expand access to Medicaid Home and Community-Based Services (HCBS) and raise wages for direct care workers.⁹ **ALL fifty states took this funding because of the extensive need for care across the country.**¹⁰ Funds from the American Rescue Plan were critical lifelines – with states

² Hart Research Associates, "Standing Up for Medicaid," April 13, 2023.
<https://caringacross.org/wp-content/uploads/2023/04/Caring-Across-Generations-Medicaid-Polling.pdf>

³ KFF, "Medicaid HCBS Waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility," 2024.

<https://www.kff.org/medicaid/state-indicator/medicaid-hcbs-waiver-waiting-list-enrollment-by-target-population-and-whether-states-screen-for-eligibility/?currentTimeframe=0&selectedDistributions=total-waiting-list-enrollment&selectedRows=%7B%22wrapups%22%7B%22united-states%22%7B%7D%7D.%22states%22%7B%22all%22%7B%7D%7D%7D&sortModel=%7B%22scrollid%22%22Location%22.%22sort%22%22asc%22%7D>

⁴ Congressional Research Service, "Long-Term Services and Supports: History of Federal Policy and Programs", Dec. 20, 2023. <https://crsreports.congress.gov/product/pdf/R/R43328>

⁵ Sarah Angell, Kezia Seales, & Lina Stepick, "Direct Care Workforce State Index: Mapping Workforce Policies and Outcomes," PHI, July 30, 2024.

<https://www.phinational.org/resource/direct-care-workforce-state-index-mapping-workforce-policies-and-outcomes/>

⁶ PHI, "Direct Care Workers in the United States: Key Facts 2024," Sept. 2024.
https://www.phinational.org/wp-content/uploads/2024/09/PHI_Key_Facts_Report_2024.pdf

⁷ Kyle D. Fee, "Using Worker Flows to Assess the Stability of the Stability of the Early Childcare and Education Workforce, 2010-2022," Federal Reserve Bank of Cleveland, Jan. 19, 2024.
<https://www.clevelandfed.org/publications/ed-reports/2024/20240119-childcare-and-education-workforce>

⁸ PHI, "Direct Care Workers in the United States: Key Facts 2024," Sept. 2024.
https://www.phinational.org/wp-content/uploads/2024/09/PHI_Key_Facts_Report_2024.pdf

⁹ Center for Medicare & Medicaid Services, Center for Medicaid & CHIP Services, "Overview of State Spending under American Rescue Plan Act of 2021 (ARP) Section 9817, as of the Quarter Ending December 31, 2023," July 2024.
<https://www.medicare.gov/medicaid/home-community-based-services/downloads/arp-sec9817-overview-infographic.pdf>

¹⁰ Ibid.

expanding services to care recipients and investing in the direct care workforce.¹¹ But these investments are short-term, and that funding is set to expire in March of 2025.

This leaves the home and community-based care system vulnerable at a time when we need greater access to services, not less. Every day in America, 10,000 of us turn 65 years-old,¹² and the number of older adults over 85 years-old is expected to more than double by 2040.¹³ As more of us, including disabled people, live longer, our nation will need more care than ever before. The direct care workforce is overwhelmingly made up of women of color and immigrants.¹⁴ These are jobs that cannot be outsourced, and won't be automated. They consistently rank among the largest¹⁵ and fastest growing¹⁶ occupations in the entire workforce because of the overwhelming demand from older adults and disabled people, particularly for direct care in the home and community. Investment in this workforce will create economic mobility for their families and communities¹⁷, in addition to stabilizing the services that caregiving families, older adults and disabled people need. We have proven solutions to this workforce crisis – including raising wages and supporting workers' rights to organize, to join a union, and to negotiate for family-sustaining wages and benefits. But this is all out of reach without increasing federal funding for Medicaid.

The proposals to increase that funding exist. Legislation to deliver care for the 710,000 people on the waiting lists for HCBS, and to raise wages for workers have been introduced, and they all have a common lead sponsor: Senator Casey. The HCBS Access Act,¹⁸ Better Care Better Jobs Act,¹⁹ Long-term Care Workforce Support Act,²⁰ and the HCBS Relief Act²¹ all increase the independence and dignity of disabled people and older adults, bolster economic security for family caregivers, and support and strengthen the direct care workforce.

¹¹ Julie Kashep, Anna Wadja, Choua Vue, and Allison Cook, "Investing in the Care Economy Works: Learning from the American Rescue Plan," The Century Foundation, Feb. 28, 2023.
<https://tcf.org/content/commentary/investing-in-the-care-economy-works-learning-from-the-american-rescue-plan/>

¹² America Counts Staff, "2020 Census Will Help Policymakers Prepare for the Incoming Wave of Aging Boomers," United States Census Bureau, Dec. 10, 2019.
<https://www.census.gov/library/stories/2019/12/by-2030-all-baby-boomers-will-be-age-65-or-older.html>

¹³ Administration for Community Living, U.S. Department of Health and Human Services, "2023 Profile of Older Americans," May 2024.
https://acl.gov/sites/default/files/Profile%20of%20OA/ACL_ProfileOlderAmericans2023_508.pdf

¹⁴ PHI, "Direct Care Workers in the United States: Key Facts," 2023.
<https://www.phinational.org/wp-content/uploads/2023/09/PHI-Key-Facts-Report-2023.pdf>

¹⁵ U.S. Bureau of Labor Statistics, "Occupational Employment and Wage Statistics: Charts of the largest occupations in each area, May 2023," https://www.bls.gov/oes/current/area_emp_chart/area_emp_chart.htm

¹⁶ U.S. Bureau of Labor Statistics, "Employment Projections: Fastest growing occupations," Aug. 29, 2024.
<https://www.bls.gov/emp/tables/fastest-growing-occupations.htm>

¹⁷ Christian Weller, Beth Almeida, Marc Cohen, & Robyn Stone, "Making Care Work Pay: How Paying at Least a Living Wage to Direct Care Workers Could Benefit Care Recipients, Workers, and Communities," LeadingAge, Sept. 11, 2020.
<https://leadingage.org/wp-content/uploads/2022/10/Making-Care-Work-Pay-Report.pdf>

¹⁸ Congress.gov, "S.762 - 118th Congress (2023-2024): HCBS Access Act," March 9, 2023.
<https://www.congress.gov/bills/118th/congress/senate/bill/762>

¹⁹ Congress.gov, "S.100 - 118th Congress (2023-2024): Better Care Better Jobs Act," January 26, 2023.
<https://www.congress.gov/bills/118th/congress/senate/bill/100>

²⁰ Congress.gov, "S.4120 - 118th Congress (2023-2024): Long-Term Care Workforce Support Act," April 15, 2024.
<https://www.congress.gov/bills/118th/congress/senate/bill/4120>

²¹ Congress.gov, "S.3118 - 118th Congress (2023-2024): HCBS Relief Act of 2023," October 24, 2023.
<https://www.congress.gov/bills/118th/congress/senate/bill/3118>

Investments in the wages and conditions for the direct care workforce are often referred to as double dignity investments because such investments not only support dignity for the workers and their families, but also the dignity of older adults and disabled people. I would add that they *also* enable dignity for working family caregivers who rely upon the support of the care workers to work. Absent these investments, we will continue to see high rates of turnover among direct care workers, impacting the quality of care and access to care for older adults, people with disabilities and their families, and care workers will continue to live in unsustainable conditions of poverty, despite their essential work. Federal investments in the direct care workforce will result in a better-trained, better-supported direct care workforce, one that will better support all who need care and our families, and decrease stress for all involved.

All of these bills are desperately needed now, but instead, older adults, disabled people, caregiving families, and workers are facing the threat of cuts to Medicaid. Any attempts to cut, cap, limit eligibility or access to, or reduce federal funding for any part of the Medicaid program will inherently harm HCBS users, family caregivers, and direct care workers. Medicaid provides health care coverage and long term services and supports for nearly 80 million children, parents, pregnant people, adults with low incomes, older adults, and people with disabilities—more than 1 in 5 people across the US²². For 7.8 million older adults and disabled people of all ages, Medicaid is the lifeline that provides home and community-based services, supporting their ability to live and age with dignity in their own homes and communities.²³ Federal funding cuts and caps will push higher costs onto states that do not have the budget to cover the differences and are already experiencing direct care workforce shortages.²⁴

Any reduction in federal funding will therefore force states to cut services and limit eligibility, which in turn will increase waitlists and damage Medicaid's critical role as a lifeline for millions of families in every community.^{25,26}

²² Center for Medicare and Medicaid Services, "August 2024 Medicaid & CHIP Enrollment Data Highlights," 2024. <https://www.medicare.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html>

²³ Caitlin Murray, Cara Stepanczyk, Alexandra Carpenter, and Andrea Wysocki, "Trends in Users and Expenditures for Home and Community-Based Services as a Share of Total Medicaid LTSS Users and Expenditures, 2022," Mathematica & Center for Medicare & Medicaid Services, Aug. 29, 2024. <https://www.medicare.gov/medicaid/long-term-services-supports/downloads/lts-rebalancing-brief-2022.pdf>

²⁴ Alice Burns, Maiss Mohamed, & Molly O'Malley Watts, "Payment Rates for Medicaid Home and Community-Based Services: States' Responses to Workforce Challenges," Oct. 24, 2023. https://www.kff.org/medicaid/issue-brief/payment-rates-for-medicare-home-and-community-based-services-states-responses-to-workforce-challenges/?utm_campaign=KFF-2023-Health-Costs&utm_medium=email&_hsmi=279618851&_hsenc=p2ANqtz-9zOZN2318V2JAheHhsNp7GHa9evQUUgeJHn5b36GcbNS1EWij2q7EX4UZ10mz2Rwnta-ycXS58fwL5GcPW10zd-fA&utm_content=279618851&utm_source=hs_email

²⁵ Dania Douglas, Michelle Yiu, & David Machledt, "Protect Medicaid Funding Issue #6: Older Adults and People with Disabilities," National Health Law Program, Sept. 2024. <https://healthlaw.org/wp-content/uploads/2024/09/06-Older-Adults-and-PWD.pdf>

²⁶ Elizabeth Edwards, Dania Douglas, & Michelle Yiu, "Helping Those on HCBS Waiting Lists: Positive Impacts of the ACA," National Health Law Program, May 16, 2023. <https://healthlaw.org/wp-content/uploads/2023/05/Helping-Those-on-HCBS-Waiting-Lists-FINAL-5-16-23.pdf>

I look forward to continuing to work with Congress and the Committee to support paid and unpaid caregivers and make it possible for seniors and people with disabilities to live and thrive in their homes and communities, by protecting Medicaid and other critical programs which provide access to essential care.

In closing, I want to thank Senator Casey for your leadership. None of the successes I outlined would have been possible without your steadfast championship, advocacy and partnership. It is daunting to think about facing the challenges ahead, particularly the threats to Medicaid, without you at the helm, but we have been emboldened to reimagine what is possible because of your leadership. Thank you.

Statements for the Record

U.S. SENATE SPECIAL COMMITTEE ON AGING

"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"

DECEMBER 12, 2024

STATEMENTS FOR THE RECORD

The American Network of Community Options and Resources Testimony

The American Network of Community Options and Resources (ANCOR) appreciates the opportunity to provide a statement for the record in response to this Committee's hearing, Empowering People with Disabilities to Live, Work, Learn, and Thrive.

Founded more than 50 years ago, ANCOR is a national, nonprofit association representing 2,600 private community providers of long-term supports and services to people with intellectual and developmental disabilities (I/DD), as well as 62 state provider associations. Combined, our members support more than one million individuals with I/DD across their lifespan, and are funded almost exclusively by Medicaid. Our mission is to advance the ability of our members to support people with I/DD to fully participate in their communities.

Chair Casey's Leadership to Support People with Disabilities

ANCOR strives to empower its members to better serve their communities by strengthening the infrastructure of Medicaid-funded I/DD services. In that work, we rely on the leadership of members of Congress to push forward legislative solutions to the barriers and challenges our members face in delivering community-based supports and services to people with disabilities. Chair Casey has been that leader.

Throughout Senator Casey's tenure on this Committee, he has consistently centered the Committee's work on pushing forward policies to uphold the dignity and equality of all people, while focusing on strengthening the supports for both older adults and people with disabilities. Chair Casey's steadfast support for legislation that empowers people with disabilities is evidenced through his leadership in passage of the ABLE Act, a seminal piece of legislation to allow people with disabilities to save without jeopardizing access to services, and advocacy for the passage of the American Rescue Plan Act, the critical relief funding that has sustained home and community-based services (HCBS) in the wake of the pandemic to name just a few of his accomplishments.

He has also continued to push forward important legislation to strengthen Medicaid Home and Community-Based Services (HCBS) through the introduction of several bills including the Better Care Better Jobs Act, HCBS Access Act, and HCBS Relief Act, as well as legislation to uphold the rights and protections for people with disabilities, such as the Transformation to Competitive Integrated Employment Act and the Ensuring Access to Medicaid Buy-In Programs Act. Chair Casey's commitment to ensuring Medicaid services can continue to carry out the promises of the Americans with Disabilities Act (ADA) has left an indelible mark on this Congress and on our communities-making them more inclusive for all Americans.

Empowering People with Disabilities in their Communities

As this Committee has acknowledged, the goal of community inclusion is fulfilled through the Medicaid HCBS program and through community providers, who offer a broad range of supports to help people with I/DD live full and independent lives in the community. However, the direct support workforce that enables the supports and services provided through the HCBS program is in crisis. In fact, results from ANCOR's 2024 The State of America's Direct Support Workforce Crisis survey found that 90 percent of community providers experienced moderate or severe staffing challenges in the past year. Due to the significant workforce shortages, our survey found that:

- 64% of community providers are delaying the launch of new programs;
- 39% of community providers have discontinued programs and services;
- 57% of case managers are struggling to connect people with services; and
- 57% of community providers deliver services in an area where few or no other options for community-based services exist.

As providers continue to grapple with high turnover and vacancy rates in the direct support workforce and inability to continue the provision of many programs and services, people with I/DD are experiencing diminishing access to community-based services and increased risk of hospitalization or institutionalization.

Congressional Action Is Necessary to Sustain I/DD Services

Given the mounting challenges community providers face in ensuring people with I/DD can continue to access critical community-based services, it is essential that Congress not neglect its role in supporting Medicaid services and strengthening the direct support workforce. We are grateful to the work of this Committee under the leadership from Chair Casey and urge the Committee to continue the important work it has begun to highlight the need for a better long-term care infrastructure, both for older adults and for people with disabilities.

We thank Chair Casey for shining a light on the importance of investing in the Medicaid HCBS program and addressing the ongoing workforce crisis. We urge this Committee to support legislation to strengthen and expand the Medicaid HCBS program through investing in the direct support workforce.

Sincerely,
Barbara Merrill
Chief Executive Officer
ANCOR

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Dr. Amy Houtrow Testimony

It is a great honor to be invited to offer a few words regarding the importance of Chairman Casey's disability policy work. In the disability justice movement, you often hear the rallying cry, "nothing about us without us!" Senator Casey has taken this to heart and brings people with disabilities to the table, makes sure they have a seat at that table, and a voice that is heard and respected. From my perspective, inclusion and belonging are the center pieces of his disability policy work. He talks the talk and walks the walk with us, regardless of how we may communicate or how we get around. I am personally grateful for how deliberate he is; how intentionally he listens. I have watched him, in both public and private settings, listen, take notes, ask follow-up questions and summarize what he has heard and what he has learned. It is remarkable to have a Senator do this. In a world where people with disabilities are marginalized, disregarded, dehumanized and discarded, Senator Casey has used his authority, time and efforts to elevate the issues faced by disabled people.

In my envisioned future, people with disabilities would have the opportunity and autonomy to live their lives as they desire without the oppressive barriers society places in front of them. Thankfully, some of these barriers are amenable to policy change. I am grateful for the various policy strategies Senator Casey has employed to pave the path toward my envisioned future. Pennsylvanians, especially disabled Pennsylvanians, and all disabled Americans have a champion in Senator Casey. I know that even after his Senate term ends, we still will.

Amy Houtrow, MD, Ph.D, MPH
(pronounced HOW-TROW, rhymes with how now brown cow, ciao for now)
Disabled pediatric rehabilitation medicine physician and
disability equity researcher Pittsburgh, PA
December 6, 2024.

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Anna Corbin Testimony

I was asked to submit a statement to be read at Senator Casey's final hearing as Chair of the Aging Committee. I find it difficult to see my laptop screen through the tears that are forming as I typed out that sentence. I want it to be noted that I am not a policy expert or a health care professional. I can only tell you what I know about Senator Casey from my place as a working class disabled mother of disabled children in the state of Pennsylvania.

I brought my children to meet Senator Casey in his office in Washington, DC in the summer of 2017. I had never sat down and spoken to a US Senator before. I wanted him to hear our story. I wanted him to understand what Medicaid had done for our family, how it had lifted us out of poverty and saved us from losing our home. I wanted him to understand how important Medicaid is to families like mine. I quickly learned that Senator Casey already had a deep understanding of the positive impacts of Medicaid. He listened intently to our story, and that day he became connected to our family. When speaking of Senator Casey, I always tell people, "He is the real deal," because he is. He does not fight for legislation or sponsor bills for the accolades or recognition. He truly cares about his constituents. He remembers their names and stories. His compassion for others knows no bounds and it is reflected in his work, and anyone who has ever met him knows it. I witnessed once, with my own eyes, an example of how remarkable Senator Casey is as a representative of the American people. I was his guest at the 2018 State of the Union address, and there was a dinner prior to the speech for all Senators and guests. While we stood in line for food, a second line had formed to our left of people - guests of other Senators - who wanted to meet Senator Bob Casey.

Senator Casey stepped out of line and met with each and every person who wanted to shake his hand. Senator Casey, you have been a beacon of light for my family in dark times. You are an inspiration to me, my husband, and our children. We will never fully be able to express how grateful we are to have had you as our Senator, and how much of a difference you have made in our lives. Please know that your absence in the Senate will be mourned by both disabled and abled-bodied people - not only in Pennsylvania, but across the entire county. Thank you for representing us so well and thank you for your service to all of us. You will be profoundly missed.

Anna Corbin, mom to Jackson and Henry Hanover, Pennsylvania
December 6, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD

Community Legal Services of Pennsylvania Testimony

Senator Casey has tirelessly advocated for Pennsylvanians with disabilities and the elderly for almost two decades. He has a track record of championing smart legislation aimed at addressing real problems faced by the community. For example, he played a pivotal role in the passage of the ABLE Act, which provides an important avenue for individuals with disabilities to save money without jeopardizing their eligibility for crucial government benefits. Many Community Legal Services (CLS) clients have been able to save money while remaining on SSI because of this helpful policy. As Chair of the Senate Aging Committee, Senator Casey has also been a stalwart and energetic leader in pushing for expanding access to quality long-term services and supports, improving due process protections in guardianship systems and protecting Medicaid, Medicare and Social Security. Among his most recent accomplishments is a comprehensive report and call to action concerning the threats posed to older adults' health and safety by hoarding behaviors.

His advocacy extends far beyond legislation. In recent years, he led efforts to highlight SSA's failure to provide benefits to children with disabilities. Senator Casey's office has played a critical role in defending against benefit cuts which would have been catastrophic. CLS has been fortunate to have such a strong partner in Senator Casey. We are grateful that Senator Casey's efforts have created tangible improvements in the lives of countless individuals with disabilities and older adults, and he is leaving Pennsylvania in far better shape than he found it.

Debby Freedman, Executive Director of Community Legal Services
Jennifer Burdick, Pam Walz, Jonathan Stein, and Richard Weishaupt, Attorneys
December 6, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Dr. Dennis B. Downey Testimony

Senator Bob Casey is the most consequential U.S. senator representing Pennsylvania in the past half century. He continues in the tradition of Tom Harkin and Ted Kennedy, working tirelessly to safeguard the welfare of individuals with disabilities and to assure their equal rights as citizens of the United States. Few of Casey's colleagues can approach his consistent and compassionate advocacy on behalf of laborers, the elderly, and children who experience some form of cognitive, behavioral, and physical disability. A leader who is modest in manner yet a force for decency and conviction, Sen. Casey has served the citizens of the Commonwealth exceptionally well. As the parent of a child (now 34 years old) with multiple disabilities, and as a scholar-advocate, I speak from experience in celebrating Sen. Bob Casey and his contribution to the common good. His efforts on behalf of families who struggle with the emotional, financial, and social challenges of living with a disability have been lifesaving. Thank you, Senator Casey.

Dennis B. Downey, Ph.D
Professor of History Emeritus, Millersville University
Past Chair, Public Interest Law Center of Philadelphia, Disability Policy Circle
Parent and Advocate
December 1, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Cindy Duch Testimony

When Senator Tom Harkin (D-IA, ret) retired, folks knew that senior citizens and people with disabilities would continue to be represented by Senator Casey as a champion for all. Senator Casey's unwavering commitment to causes that had long been ignored or passed over were in the spotlight and we were represented by someone who felt the passion that disability advocates also felt. He understood. He took the time to understand, he listened and he acted.

For our family, and especially for my son Andrew, Senator Casey's passing of the ABLÉ Act has ensured that Andrew's future is the future he wants. Andrew was able to save money to buy a car. It was a huge achievement when Andrew got his driver's license. Of course, after that came the car! And Andrew was ready. When Senator Casey was working to pass the ABLÉ Age Adjustment Act, Andrew was tapped to present on a panel that spoke to the positive outcomes from having an ABLÉ account. Andrew wanted nothing more than to support Senator Casey in passing this Act because of the impact the ABLÉ Act and having an ABLÉ Account has had on Andrew's life and will continue to have.

I know that Senator Casey will continue to champion those he worked so very hard for. Andrew's family wishes the absolute best to one of the most sincere and hardworking representatives for the Commonwealth of PA. Godspeed Senator Casey.

Cindy Duch
The Family of Andrew Duch
December 2, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Gary Blumenthal Testimony

For 18 remarkable years, Senator Bob Casey has been a steadfast advocate for the people of Pennsylvania, championing the rights and well-being of our most vulnerable citizens. His dedication to children, the elderly, and people with disabilities reflects a deep compassion and understanding of the challenges faced by those who rely on public officials with unwavering empathy and commitment. Senator Casey's pivotal role in safeguarding Medicaid and the Affordable Care Act stands as a testament to his courage and determination to protect essential lifelines for millions of Americans. His leadership has not only served as a shield against threats to these vital programs but has also inspired hope and trust among countless individuals and families across the Commonwealth and the nation.

Senator Casey's legacy places him among the great "Lions of the Senate," alongside figures such as Ted Kennedy, Tom Harkin, Robert Dole, and Orrin Hatch, who fought tirelessly for equity and justice. His extraordinary ability to prevent the repeal of the Affordable Care Act and resist misguided attempts to convert Medicaid into a block grant underscores his effectiveness and resolve. As someone who witnessed his work up close, I can attest to his genuine collaboration with constituents and advocates, amplifying the voices of those too often unheard. Senator Bob Casey will be remembered as a beacon of hope and a true protector of the vulnerable, leaving an indelible mark on Pennsylvania and the nation.

Gary Blumenthal
Vice President, Governmental Relations and Advocacy, InVision Human Services
Former Member, The National Council on Disability
December 6, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Eugenia Bond Testimony

My name is Eugenia Bond the CEO of Penn-York Opportunities, Inc. in Bradford County, PA. We have been proudly serving people for nearly 60 years. We serve and have served those whose lives are impacted by a variety of factors including disability, poverty, endangered children, people who are facing homelessness, food insecurity, employment challenges and many other things. We assist people in their daily lives for health and safety, social immersion in the community as well as employment support. We are proud that we have two small businesses that were developed specifically to employ those with disabilities. For a small community we are heavily involved and intertwined to make where we live a better place.

Senator Casey, your work with the Bipartisan Bill ABLE directly impacted those we serve by helping them to achieve even more independence and thrive in a world filled with challenges. This is just one of many examples of your dedication and hard work for underserved Pennsylvanians. We value and respect all that you and your team has done for those with disabilities. Further, we are grateful that your staff came in person to meet with us all the way up here in rural NEPA to be introduced to our programs and explore opportunities and solutions to access additional resources. Your boots on the ground approach have made a difference and your staff continues to support us with helping to bridge the gap of transition to a new administration. You and your team do exactly what I would think everyone would want from leaders in our government. You are informed, involved, active and present for those that need it the most. Thank you again for all that you have done and for your service.

Best Regards -
Eugenia Bond, BSW, MOL
Chief Executive Officer
Penn York Opportunities
December 5, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Jacquelyn M. White Testimony

As a mother of three kids with disabilities and special health care needs, complex needs that I would need a book to adequately explain here, I want to reiterate the importance of the work that Senator Casey has conducted regarding this community. No other senator in congress has people devoted to policy work for the disabled/aging population in such a paramount way. Even with the current programs in place I genuinely fear the future for my children and other people with disabilities if we don't continue to focus on pivotal supports, programming, and policy to support people with disabilities-which remains the largest minority group in the United States.

I live, work, and play in Pennsylvania, in addition to being a mom, I work in the field of disability advocacy. We have so far to go, so far, but so much has been improved because of the tireless efforts of the Casey team and colleagues. As a mom, I ask that we don't let the work done here be in vain. Disability rights should not be partisan, they should be human. I think we all can resonate with human. I can't thank Senator Casey and his team enough for all the work they have done in Pennsylvania, and beyond. Gratitude and grit abound.

Thank you,
Jacquelyn M. White (Mom and Advocate)
December 3, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Jonathan Cunningham Testimony

Senator Bob Casey and his team have been absolute champions for our organization and those we serve here in rural Pennsylvania. Of the many efforts they have made for us, perhaps the most meaningful is that they have actually taken the time to listen. Quite often, the needs and struggles of rural citizens get overlooked, especially those living with disabilities. Senator Casey, and the key staff under his leadership, have taken the time to meet with those we serve, listened as they described the real world obstacles they must navigate, and have gone to bat for us as we've needed additional funding to move our mission further. We will forever be grateful for your commitment and friendship Bob, and for all that you've done for this country's most vulnerable citizens.

Jonathan Cunningham, President/CEO
NuVisions Center
Lewistown, PA
December 6, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Jule Ann Lieberman Testimony

I am an older blind woman living in Pennsylvania who uses assistive technology software to access information and services on the Internet. Senator Casey has led the way to illustrate the failure of many federal websites to meet accessibility guidelines. He has referenced the "Digital Front Door" and how many of us with blindness and low vision are locked out. This results in limited or no access to critical national information or application to vital federal services most notably to our disabled veterans. Senator Casey recognizes the need for all to have access to information and services with privacy and independence regardless of disability. I will be forever grateful to Senator Casey for his efforts to remove the lock from the "Digital Front door" and hope his efforts will continue beyond his work in the US Senate.

Respectfully Submitted,

Jule Ann Lieberman, MS CLVT/CATIS
Advocate for Accessibility for Blind and Low Vision
TechOWL, Institute on Disabilities at Temple University
December 5, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Julia Barol Testimony

Dear Senator Casey,

I am writing to express my heartfelt gratitude for your ongoing commitment to advocating for individuals with disabilities. Your leadership and dedication to ensuring inclusivity and equal opportunities have made a profound impact on the lives of countless people across our nation.

Your efforts to strengthen the Americans with Disabilities Act, champion inclusive education, and support disability employment initiatives are truly commendable. These actions demonstrate your unwavering belief in the inherent value and dignity of every individual, regardless of ability.

As someone deeply connected to the disability community, I have witnessed firsthand how your work has brought hope, opportunity, and a sense of belonging to many who have faced systemic barriers for far too long. I know firsthand how critical it is to have leaders like you who understand the importance of inclusion and stand up for the rights of all individuals.

Thank you for standing as a tireless ally for those who often go unheard. Please know that your work has been greatly appreciated and inspires many of us to continue striving for a more inclusive and equitable society.

With deepest appreciation,
Julia Barol, MEd, CESP
President and CEO
Bala Cynwyd, PA

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Kate Dempsey Jones Testimony

It is difficult to summarize the many ways Senator Casey has supported Scranton and the surrounding community during the last 17 years. A steady and impassioned voice for underrepresented citizens; a champion for economic development, housing, income equity, healthcare, and disability rights; Senator Casey embraced the belief that our community is stronger, built with the values of diversity, equity, inclusion, and access to a life of dignity and purpose for all citizens.

As a leader in the US Senate, representing all Pennsylvanians, Senator Casey has always demonstrated respect, compassion, and kindness to all he served. Goodwill Industries of Northeastern PA was engaged in a 20+ year struggle to restore the abandoned North Scranton Junior High School, a cherished community landmark, and create affordable senior housing. The project finally came to fruition because Senator Casey recognized both the community need and economic impact of such a project. Thanks to Senator Casey, Goodwill Industries of Northeastern Pennsylvania proudly provides affordable senior living in 58 beautifully restored apartments in a building equipped with many amenities including an 800-seat community arts theater.

We are forever grateful to Senator Bob Casey for his many years of dedicated service, and we are honored to have been represented by a man who is the embodiment of honesty, integrity and character.

Sincerely,

Kate Dempsey Jones, CEO
December 9, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Kathy Brill Testimony

Dear Senator Casey,

On a personal note, I can't thank you enough for the focus you have placed over the last 18 years on disability issues! My now adult daughter, who has a disability, has benefitted tremendously from your term as Senator. She has an ABLE account, lives in a home of her own with the supports of Medicaid and SSI, and is employed part-time. It is our hope that as she ages, the disability policy work you've done will continue to brighten her path through life. Our entire family is deeply saddened to lose your strong leadership. Please know that we will continue to have incredible respect, admiration, and support for you.

PennTASH, a disability advocacy organization to which I belong, would also like to extend its deepest gratitude to you for the work you've done over the years. "We would like to commend your insurmountable hard work advocating for the needed supports to create better lives for those with disabilities and aging. You will be sorely missed by not only all of us, but the entire nation."

Respectfully,

Kathy Brill
Parent, Advocate, and PennTASH Board Member
December 5, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Liberty Resources, Inc. Testimony

Accessible, affordable, integrated housing, guardianship reform, independent living, public transportation, HCBS & DCW/Caregiver equity and ending the institutional bias in long-term care. These are just a few of many strategic systems improvements that Senator Bob Casey led and advanced for our disabled communities in Pennsylvania and across our great Nation.

Liberty Resources and our many Consumers recognize you as our champion of our civil rights in the U.S. Senate. We thank you for your 18 years of service and appreciate everything you did for us to make sure that people with disabilities are a truly integrated part of the American dream.

Thomas Earle, CEO
Liberty Resources, Inc. (the CIL for the Philly/SE Pa area)
December 5, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Linda Carmona-Bell Testimony

I heard Senator Casey speak in 2007. He shared his passion, plans, and commitment to addressing the needs of children and families. Fast forward to today, he has delivered on his commitments! He has made a difference in my 24-year-old adult daughter's life and those of many others. With his leadership in passing the ABLA Act, the Affordable Care Act, and the Campus Sexual Violence Elimination Act, he has changed lives!

Thank you, Senator Casey, for being true to your faith by ensuring all children are valued and safe. May our Lord continue to bless you this Christmas season and always in all you do!

Sincerely,

Linda Carmona-Bell
President
Pennsylvania Education for All Coalition, Inc.
December 6, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Lisa Lightner Testimony

Senator Casey's was first elected just a mere couple of months after my disabled child was born. At the time, I was so busy doing all the "new mom" stuff that I certainly didn't realize then what an impact he'd have on our lives. Over the past 18 years, his steadfast advocacy has amplified the voices of families who are often silenced. From championing accessible healthcare to protecting the rights of our children under IDEA, his work has been a shield against a system that can feel unrelenting.

For my son Kevin and me, Senator Casey's dedication became deeply personal during the turbulent ACA repeal attempts of 2017 and 2018. When healthcare-and with it, Kevin's future-was on the line, his office became our ally. They didn't just hear us; they fought alongside us. Bob Casey's tenure in the Senate has been a lifeline for the disability community, a reminder that genuine leadership makes a difference. Families like mine don't forget that kind of support and you will be missed terribly.

Lisa Lightner
Mom and Special Education Advocate
Avondale, PA
December 5, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Mark Friedman Testimony

Senator Casey's long commitment to advancing disability and aging policies has helped thousands of people with disabilities and their families. His leadership in promoting home- and community-based services and governmental policies has made a huge difference in the lives of so many people.

Senator Casey's work has shown how government can help the most vulnerable people.

I first started working in the field to free people living at Pennhurst 40 years ago. I have seen momentous changes over the decades. I am deeply grateful for Senator Casey's work to make this happen.

Sincerely,

Mark Friedman, CEO, Blue Fire, Inc. Ardsley, PA
December 5, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Matt Aaron Testimony

Senator Casey has been a steadfast champion for individuals with intellectual disabilities all over the Commonwealth. Thanks to his tireless efforts over so many years, Special Olympics PA (SOPA) has been able to provide more than 15,000 Healthy Athlete screenings in seven different disciplines to help address the significant health disparities our athletes face, and, later this school year, we will surpass 500 schools participating in our Unified Champion Schools program.

Senator Casey's support was particularly helpful after the COVID pandemic, which decimated SOPA's membership rolls. With his help, SOPA was able to deliver a combination of activities that included health screenings and sport clinics. These activities incorporated innovative elements, such as Athlete Performance Training and Unified Fitness, designed to help athletes improve their overall health and fitness. As a result, SOPA has been able to recapture more than half of the athletes lost during the pandemic.

On behalf of more than 15,000 Special Olympics PA athletes, thank you Senator Casey for always being there to support individuals with disabilities!

Matt Aaron
CEO and President
December 6, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Maureen Cronin Testimony

I write to honor the most courageous Senator Casey. He is the best example of the perfect legislator, truly knowing all of Pennsylvania and his constituency. There is not a part of Pennsylvania that he did not personally visit. He visited so many Chapters of The Arc across Pennsylvania. When visiting our Chapters, he listened and learned. When advocates, particularly self-advocates, shared their experiences, they were respectfully listened to, and their words were taken to heart and then acted on. Many important disability related pieces of legislation were enacted thanks to Senator Casey.

This humble, soft-spoken statesman is a well-loved, fierce advocate for people with disabilities and their families. He was the first leader to speak of the "sandwich generation," especially as it relates to those caring for elder parents while caring for adult sons and daughters with disabilities. Senator Casey also had the wisdom and forethought to hire a Disability Policy Director, Michael Gamel-McCormick, to advise him and yet be a strong disability leader and connector across Pennsylvania.

I look forward (after a well deserved rest) to seeing the next chapter of the Senator's work and wish him the very best.

Maureen Cronin
Former Executive Director, The Arc of Pennsylvania
December 4, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Meghann Luczkowski Testimony

The opportunity to give a statement about Senator Casey for his final meeting as Chair of the Aging Committee was just shared with me, and I wanted to send something over. I give permission to read this statement at the hearing and enter it into the Congressional record:

Parents of disabled children know the world was not built for our kids. Systems of care and education were not initially designed with disability and complex medical needs in mind. Providing extraordinary levels of care for our children while constantly battling for their individual wellbeing often means we don't have the time or energy left to advocate on a bigger scale, and the systemic changes needed continue to go unnoticed.

Senator Bob Casey opened his eyes to our families and saw the needs of our children. He opened his ears and listened to our lived experience. He opened his heart and genuinely cared about improving our children's situations, and as Senator of Pennsylvania, time and again, he opened his mouth to fight for our kids' access to care and to their community. It will always be scary sending our disabled children out into the world, but with Senator Casey representing us, we could rest assured knowing they had a champion in Washington.

Meghann Luczkowski
Caregiver and Disability Advocate
Philadelphia, PA
December 6, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Nancy Murray Testimony

People with disabilities and their families, in Pennsylvania and throughout the United States, owe Senator Casey a debt of gratitude for his advocacy on our behalf. Senator Casey has long been considered one of the United States Senate's leading champions on disability policy and with good reason. Senator Casey has been a leading voice defending the Affordable Care Act and Medicaid. Over the course of his political career, Senator Casey has introduced dozens of bills to advance the civil rights and quality of life for people with disabilities. The Achieving a Better Life Experience Act, or ABLE Act, is perhaps his signature achievement. However, he also passed subsequent bipartisan legislation, the ABLE Age Adjustment Act; and most recently, he introduced the Ensuring Nationwide Access to a Better Life Experience Act that would further expand what ABLE accounts can do for disabled people and family caregivers.

What I will forever remember about Senator Casey however is his kindness, his genuine interest in people with disabilities, and his willingness to spend time listening to us. Every year during the Arc of the United States Disability Seminar we would schedule time to meet with Senator Casey and he never disappointed us. Some years, he would leave the Senate Chamber and meet us at his office. When our group was too large to fit in his office, he would meet with all of us in the hallway outside his office so that we all could spend time with him. Thank you Senator Casey for those memories and for your advocacy on our behalf. You will never be forgotten.

Nancy Murray
Parent advocate of three adult children with disabilities
Retired VP of Achieva and President of The Arc of Greater Pittsburgh
December 1, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Nancy Thaler Testimony

There are many achievements in Senator Casey's decades of service to the citizens of Pennsylvania, as the state's Auditor General, as the State Treasurer and for the past 18 years, as Senator. Sometimes, it is difficult for people to name something an elected official did that made a difference in their life, but in regard to Senator Casey, there are thousands of people whose lives have been greatly improved through the ABLE Act - and they know exactly who made it possible. My son Aaron is one of those people. His ABLE account allows him to save his earnings without fear of losing his home and community-based services. He is extremely proud to have a savings account and to know that if an expense comes up that Medicaid does not cover, he can take care of it. He feels empowered and is proud.

Nancy Thaler,
A constituent and Aaron's mom
December 5, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD

James W. Conroy and Karen Ann Hayes Testimony

Thank You to Bob Casey for Disability Advocacy December 11, 2024. A little group of disability advocates in Pennsylvania today offers its praise affection and gratitude to our friend and ally senator Bob Casey. Bob comes from a state that is one of the epicenters of the disability rights movement in America. The Right to Education, the Right to Treatment, and the Right to Community Living, were three of the milestone legal and civil rights attainments that took place in our Commonwealth. Bob knows this history well, and always supported our efforts above and beyond the call of duty.

Bob, you represented and led with respect and dignity, and did so with tremendous courage, integrity, and honor. You always encouraged our work, and we know that in whatever roles you adopt in the future you will continue to enjoy supporting our goal of a national place of learning and memory about the disability rights movement in America, so Thank You from the Pennhurst Memorial & Preservation Alliance.

Sincerely,

James W. Conroy and Karen Ann Hayes, Co-Presidents

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD

Pennsylvania Statewide Independent Living Council (PA SILC) Testimony

We are the Pennsylvania Statewide Independent Living Council (PA SILC). Our work focuses on support for the PA 16 Centers for Independent Living (CILs) and other disability organizations in performing systems advocacy on various issues, such as support for CILs, accessible and affordable housing and transportation, community employment, improving community accessibility, and other disability needs (voting, emergency preparedness, etc.).

Our organization would like to thank Senator Casey and his staff, particularly Michael-Gamel McCormick, for their efforts over the years for people with disabilities on budget and policy matters since 2007. While there are a number of disability or related areas where efforts could be noted during his 18-year tenure in the US Senate, we highlight several areas of accomplishment. First, is the passing of both ABLA Accounts (2014) and ABLA Age Adjustment Act (2022) which created the disability savings accounts (up to age 26) and expanded the age availability up to age 46. Senator Casey has worked to overturn the institutional bias in Medicare and Medicaid toward nursing facilities and other institutional care in funding and policy. While there is still work to be done, because of him, disability employment is now more focused on community opportunities instead of sheltered workshops and sub-minimum wage settings. The Senator and staff have been instrumental in helping CILs, other disability partner organizations, and our state government to obtain federal funding through the budget process for non-profit organizations and accessible / affordable housing (811 program). We appreciate his efforts on Guardianship reforms with a key stakeholder hearing and legislation -we look forward to future efforts by Congress based on his hearing in 2023 and the outreach done on this issue. During the Covid-19 period, his support was vital in providing necessary resources.

During our annual visits to the National Council on Independent Living (NCIL) Conference, the Senator and his staff have been helpful in coordinating our visits and helping with navigating the capital. The Senator has been a frequent speaker at the annual NCIL Conference and rallies during the annual march. Both Senator Casey and his staff visited and listened to CILs in urban, suburban, and rural settings during time in his Pennsylvania district. His district staff has been helpful, attending local gatherings, and assisting with casework by providing resources. While some members of Congress show up and offer to help, he and his staff have done that and more. We thank both Senator Casey and his staff in both Washington DC and the district for their efforts. Best wishes for a bright future. You are missed already.

You have our permission to read this during the US Senate Aging Committee hearing in mid-December.

Susan Tomasic,
PA SILC Board Chair
Matthew Seeley, Esquire
PA SILC Executive Director
December 3, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
 "EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
 DECEMBER 12, 2024
 STATEMENTS FOR THE RECORD

**Pennsylvania Advocates and Resources for Autism and Intellectual
 Disabilities (PAR) Testimony**

Thank you for the opportunity to provide testimony today. I am Mark Davis, President & CEO of the Pennsylvania Advocates and Resources for Autism and Intellectual Disabilities (PAR). We are saddened by the loss of disability champion, Senator Bob Casey. We will miss his long-tenured and diligent work to support people with intellectual disabilities and autism (ID/A). Senator Casey's tireless efforts resulted in numerous improvements to supports for seniors and people with disabilities. A few examples in Pennsylvania are:

- According to the Center for Disability Information (CDI) without the support of ARPA for our system, almost 12,000 more individuals with ID/A would have been infected with COVID-19, and over 500 more people with ID/A would have died in Pennsylvania alone
 - Increasing access to home and community-based services
 - Improving staff recruiting and retention
 - Providing necessary supplies to safely facilitate services
 - Supporting the DSP workforce with additional trainings and learning opportunities
- Supporting families caring for their loved one
- Improving functional capabilities of people with disabilities
- Enhancing transitional supports
- Building capacity for much-needed home and community-based services.

Sen. Casey recently chaired a committee hearing on the direct support professional (DSP) workforce, shedding light on the DSP crisis and the impact on people with intellectual disabilities and autism. Sen. Casey has left a legacy through his senatorial service that will benefit Pennsylvanians and other Americans with ID/A for years to come. I look forward to watching the chairman's next chapter unfold. I am confident he's not done helping people with disabilities. Godspeed Senator Casey.

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD

Pennsylvania Autism Society of America Testimony

On behalf of the Autism Society of America and its Pennsylvania affiliates including Autism Society Berks County, Autism Society Greater Harrisburg Area, Autism Society Greater Philadelphia, Autism Society Lehigh Valley, Autism Society Northeastern Pennsylvania, Autism Society Northwestern Pennsylvania, and Autism Society Westmoreland, we extend our deepest gratitude to Senator Bob Casey for his unwavering commitment to improving the lives of individuals with autism and other developmental disabilities. Throughout his distinguished career in the Senate, Senator Casey has been a tireless advocate for inclusion, accessibility, and equity, ensuring that individuals with disabilities and their families are not left behind. His leadership on critical legislation, such as the ABLE Act and extraordinary efforts to expand Medicaid home and community-based services and supports, has made an indelible impact on countless lives across Pennsylvania and the nation.

We celebrate his legacy of compassion, dedication, and action. Senator Casey's voice has been a powerful force for progress, and his work has set a strong foundation for future champions of disability rights. The Autism Society thanks him for his partnership and advocacy and looks forward to continuing the work to build a more inclusive society.

The Seven Pennsylvania Autism Society Chapter
December 3, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD

Pennsylvania Department of Human Services Testimony

For the length of his tenure in Congress, Senator Casey has been the vanguard for federal policy on disability rights and services which has resulted in transformative change for this community across the United States and in the Commonwealth of Pennsylvania. The depth and breadth of his understanding of the issues facing individuals with disabilities and their families, as well as disability service systems, paired with his corresponding commitment to advancing solutions, is unmatched. Of particular note from a state perspective, Senator Casey was a key voice in ensuring that Medicaid-funded home and community-based services were funded during and post-pandemic. COVID-19 was especially devastating for people with disabilities and the service systems on which they rely. Senator Casey championed significant funding through both the CARES Act and the American Rescue Plan Act (ARPA), providing states with the essential resources to shore up and then improve service delivery.

Though Senator Casey is well known for the ABLE Act, he should also be recognized for a deceptively small provision he championed through passage, the Medicaid coverage for home and community-based services in acute hospital settings. The prior prohibition on home and community-based service delivery while someone was hospitalized meant that, for decades, individuals with intellectual and developmental disabilities without a family caregiver who were hospitalized and needed support with communication or decision-making could not fully participate in their own diagnosis and treatment. This often led to traumatic hospital stays, poor care, and unnecessary suffering. Though this issue potentially impacts less than 2% of Americans he saw the illogic of this policy and the pain it caused. Senator Casey provided a remedy.

On behalf of Pennsylvania's Department of Human Services, we honor and celebrate Senator Casey's immensely impactful and enduring contributions to this critical area of public service.

Valerie A. Arkoosh, MD, MPH
Secretary, Pennsylvania Department of Human Services
Kristin Ahrens
Deputy Secretary, Office of Developmental Programs, Pennsylvania Department of Human Services
Juliet Marsala
Deputy Secretary, Office of Long Term Living, Pennsylvania Department of Human Services

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD

The Partnership for Inclusive Disaster Strategies Testimony

Thank you Senator Casey for being an outstanding senator and a stalwart champion for disabled people. You introduced the Real Emergency Access for Aging and Disability Inclusion for Disasters Act (REAADI) as well as the Disaster Relief Medicaid Act (DRMA) the past couple of sessions. REAADI would have, and we still hope will, provide research, training and technical assistance in efforts to increase the survivability of people with disabilities and older adults throughout disasters. DRMA, if enacted, would make Medicaid portable for disabled disaster survivors. Both laws would save lives. Lives of disabled people who are two to four times more likely to be injured or die in a disaster than nondisabled people. By introducing them you shined a light on the ableism and discrimination encountered by disabled people and older adults in disasters. You supported disabled people when others denied the inequity we confront in every disaster. You supported us when others refused to prioritize equity for disabled people in disasters, and you didn't let resistance stop you from reintroducing both pieces of legislation twice. You trusted the Disability Community when we presented solutions to meet our needs. On behalf of disabled people who have survived disasters and the disproportionate numbers of those of us who have not survived, we thank you.

Shaylin Sluzalis (SHAY-lin SLU-zah-lis)

And

Germ n Parodi (Her-MAHN Pa-RO-dee (with a rolled "r" for Germ n, if possible)
Co-Executive Directors of The Partnership for Inclusive Disaster Strategies

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Stacy Jarett Levitan Testimony

Senator Casey's disability policy work has been life-changing for people with disabilities, not only in Pennsylvania, but in the United States. He truly understands the potential that people with disabilities have to contribute meaningfully to our communities and has been committed to removing barriers preventing opportunities.

Senator Casey's actions throughout his career have thoughtfully enabled people with disabilities to live where they want and work in rewarding jobs where they are paid a competitive wage. He has centered people with disabilities in his work so that people with disabilities make the decisions about their own lives and indeed, decide what governmental policy will be regarding issues that matter to them. All his work has enhanced the nation's understanding of how much better our country will be when people with disabilities live lives of self-determination and are able to use their talents to better our communities.

Stacy Jarett Levitan
Executive Director, Judith Creed Horizons for Achieving Independence (JCHAI)
December 5, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD

Institute on Disabilities at Temple University Testimony

Today, the Institute on Disabilities at Temple University joins others in the disability community in recognizing the dedication and tireless work of Pennsylvania's Senior Senator Robert P. Casey.

Learning and working alongside people with disabilities and their families is essential to our work. Over the past seventeen plus years, we have enjoyed the privilege of watching Senator Casey learn from and work alongside Pennsylvanians with disabilities and their families. While his contributions to the disability community are too numerous to mention, one piece of legislation that stands out is the ABLE Act. True to its name, the Achieving a Better Life Experience Program or ABLE, recognizes that people with disabilities need not live in poverty in order to qualify for essential Home and Community-Based Services. ABLE created a path to saving for a better future for many of the Pennsylvanians with disabilities we serve because Senator Casey listened to the needs of the community, and then introduced and advocated for passage of this impactful legislation.

Senator Casey, we are proud to call you an Ally and humbled to call you a friend. Thank you for your service.

Respectfully,
Sally Gould-Taylor PhD, Executive Director, Institute on Disabilities at Temple University
Jamie Ray-Leonetti, JD, Associate Director of Policy, Institute on Disabilities at Temple University
December 4, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Sherri Landis Testimony

Senator Casey has devoted his three terms in the U.S. Senate to being an unwavering advocate for people with disabilities. He was instrumental in the creation of the ABLE Act and recently spearheaded the passage of the ENABLE Act, which permanently enshrines the ABLE Act's provisions into law, ensuring that individuals with disabilities can benefit from tax-advantaged savings accounts. Throughout his tenure, he has consistently championed efforts to improve Medicaid home and community services. Every piece of legislation Senator Casey introduced that impacted the disability community reflected his deep belief that people with disabilities deserve the resources and support necessary to live and work in their communities.

During the pandemic, Senator Casey reinforced his commitment by regularly meeting with Pennsylvania self-advocates and disability stakeholders, gaining first-hand insight into the challenges they faced. The Arc of Pennsylvania has always recognized Senator Casey as a trusted ally in Washington, prioritizing the needs of people with disabilities. His advocacy extended beyond his role as a Senator—he truly understood and valued the potential of individuals with disabilities, creating a deep sense of trust and understanding within the disability community. He spoke our language, understood our needs, and remained a steadfast champion for the rights of people with disabilities across Pennsylvania and the nation. On behalf of The Arc of Pennsylvania Board of Directors and staff, we extend our heartfelt gratitude to Senator Casey. Your dedication and hard work will always be remembered and deeply appreciated.

Sherri Landis, Executive Director
The Arc of Pennsylvania
December 3, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Katy Neas Testimony

On behalf of The Arc of the United States, I wish to express my deep gratitude to Senator Casey for his decades of service and unwavering commitment to protecting the rights of people with disabilities. Throughout his tenure, Senator Casey's leadership has been instrumental to advancing policies that promote inclusion, self-determination, and dignity for all. People often show who they truly are in times of crisis. From the many battles to protect and strengthen Medicaid, to the darkest days of the COVID-19 pandemic, Senator Casey showed himself to be not just an ally but a champion for the disability community. As chair of the Senate Aging Committee, he took on critical threats to the lives of people with disabilities—strengthening Home and Community Based Services and addressing the Disability Support Professional workforce crisis.

He also fought to ensure that people with disabilities have the resources and opportunities they need not just to survive, but to thrive. We commend Senator Casey for his many legislative achievements, including but limited to his leadership of the Stephen Beck Jr. Achieving a Better Life Experience Act, or ABLE Act. This landmark legislation has empowered people with disabilities to save money for future needs with the peace of mind that they can maintain access to lifeline benefits. We thank Senator Casey for his dedication, his vision, his leadership, and for being a steadfast advocate for people with disabilities. His work will continue to make a lasting difference in the lives of people with disabilities, their loved ones, and our Nation.

Katy Neas, Chief Executive Officer, The Arc of the United States
December 6, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Dr. Tina Paone Testimony

Senator Bob Casey's work to prevent elder abuse, neglect, and exploitation, including financial exploitation of seniors, has had an impact on thousands of elderly Pennsylvanians. Selected to share my mother's story of financial exploitation at the Guardianship and Alternatives: Protection and Empowerment, provided me with a platform to share the concerns of so many aging Pennsylvanians tangled in the guardianship system. As a result of being provided with this national platform, local officials heard the call to action. Within months of my testimony, we were made aware that the court-appointed guardian we had removed also resigned as guardian from the hundreds of other cases in which they were involved. This would not have been possible without the support of Senator Casey.

During this same hearing, the introduction of the Guardianship Bill of Rights, was presented. It is the hope that bill will move forward with the new administration of the Special Senate Committee on Aging. It will not only benefit Pennsylvanians, but the elderly population nationwide.

Dr. Tina Paone
Professor & Licensed Professional Counselor
Monmouth University
December 6, 2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Tom Carasiti Testimony

Senator Casey will be missed by the individuals and families of the Pennsylvania disability community. As a parent and advocate for the developmentally disabled, it was truly comforting to know Senator Casey and his staff had our backs when it came to championing the policies and needs of our families. All good causes need representation in Washington. It's difficult to imagine anyone else representing us to the level he provided. Senator Casey and his team were always accessible to hear and address our concerns. His mere presence in Washington, just that alone, gave us comfort knowing he would always guide legislation to improve our lives. We thank him immensely for his work, and wish him the very best in his next endeavors.

Sincerely,
Tom Carasiti Pennsylvania Waiting List Campaign Philadelphia, PA December 6,
2024

U.S. SENATE SPECIAL COMMITTEE ON AGING
"EMPOWERING PEOPLE WITH DISABILITIES TO LIVE, WORK, LEARN, AND THRIVE"
DECEMBER 12, 2024
STATEMENTS FOR THE RECORD
Vision for Equality Testimony

Senator Casey's unwavering commitment to advancing disability policy has had a profound and lasting impact on the lives of individuals with intellectual and developmental disabilities across Pennsylvania and beyond. Your leadership as Chair of the Aging Committee and your steadfast advocacy for inclusive policies have given a voice to those who are often unheard, creating opportunities for independence, dignity, and belonging. From strengthening access to essential supports and services to championing the rights of individuals with disabilities, your work has touched countless lives and empowered families to thrive.

You will be deeply missed by the disability community, not only for your accomplishments but also for your genuine compassion and dedication to ensuring that all people, regardless of ability, can lead fulfilling lives. As we celebrate your legacy, Vision for Equality extends our heartfelt gratitude and best wishes for the next chapter of your journey.

Thank you, Senator Casey, for being a true advocate and ally,
Audrey Coccia and Maureen Devaney, Co-Executive Directors
Vision for Equality
Philadelphia, PA
December 6, 2024